ENVIRONMENTAL COPING EMPLOYED IN THE HOME ENVIRONMENTS OF PERSONS WITH ALZHEIMER'S DISEASE

by

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CHAPTER ONE

INTRODUCTION

Alzheimer's disease, a degenerative brain disorder, affects millions of Americans (Gwyther, 1985). Alzheimer's disease patients, whether they live at home or in a long-term care facility, create special problems for caregivers. Much current research has focused on the special needs of these patients and on the quality of care they receive (c.f., Calkins, 1988; Cohen, Weisman, Ray, Steiner, and Toyne, 1988; Pynoos, Cohen, and Lucas, 1988; and Pynoos, Liebig, Hultman, and Searle, 1989). As a part of these efforts, researchers have recognized that the physical environment can play an important role in the management and care of these patients. Most of this work has focused on issues dealing with environmental interventions and management of Alzheimer's disease within institutional settings (Gilhooly, Zarit, and Birren, 1986). Although a large number of elderly persons with Alzheimer's disease are in hospitals or nursing homes, the majority are cared for in the home (Kwon, 1988).

This study examines how changes in the residential environment affect the abilities of caregivers caring for Alzheimer's disease patients to care for the patients at home. First, this study describes what types of

environmental interventions are being employed by caregivers, and which ones they perceive as being effective. Second, it focuses on the role of managing the physical environment of the patient's home as a source of stress and control perceived by caregivers. Third, it examines the use of environmental interventions within the context of all coping strategies caregivers use to respond to memory and behavior problems. Finally, the study offers suggestions for residential environmental interventions to be used by designers and caregivers, based on these types of information.

Significance of the Problem

The number of Americans 65 and older is growing at an unprecedented rate. Because more people are living longer than the ever before, dementia (the loss of mental functions in an alert and awake individual) will constitute a large and growing public health problem well into the next century. Heston and White (1983), predict that "thirty percent of the those who live into their later years will contract some form of dementia..".

> Today, an estimated 1.5 million Americans suffer from severe dementia -that is, they are so incapacitated that others must care for them continually. An additional 1 million to 5 million have mild or moderate dementia. Ten times as many people are afflicted now as were at the turn of the century. The number of people with severe dementia is expected to increase 60 percent by the year 2000. Unless cures or means of prevention are found for the

> common causes of dementia, 7.4 million Americans will be affected by the year 2040 - five times as many as today (U.S. Office of Technology Assessment, 1987, p.3).

Senile dementia of the Alzheimer's type (SDAT), or Alzheimer's disease, as it is commonly called, is the most common cause of severe mental deterioration in later life. Alzheimer's disease is an organic, degenerative, progressive disorder of the brain cells. Alzheimer's disease afflicts between 2,000,000 and 4,000,000 Americans. It is the fourth leading cause of death for Americans age 65 and older (after heart disease, cancer, and stroke), accounting for 120,000 deaths a year. The cause of Alzheimer's disease is not fully understood and currently there is no cure. Although Alzheimer's disease is only one type of dementia, it accounts for almost 50% of all dementia cases (Calkins, 1988).

There are two victims of Alzheimer's disease: the patient and the caregiver. Because of the progressive and eventually complete deterioration of the patient, that person becomes totally dependent upon others for care. Therefore, the caregiver gradually must assume total responsibility for the patient. There are few other diseases that involve the families so much or have such devastating effects. "Of all the incurable diseases, the degenerative brain disorder known as Alzheimer's may be the cruelest, because it kills its victims twice" (Newsweek, Dec.3, 1984, p.56). In Alzheimer's, the mind dies first,

then the body. This process is stressful and sometimes devastating for the family and friends who must witness the erosion of the mind and personality of the patient.

Alzheimer's disease has received much attention in the past decade. While this attention has helped generate public understanding and research, according to Lawton, "the push to deal with Alzheimer's disease has tended to focus our attention on the biology of the illness and an eventual pharmacological treatment" (Calkins, 1988, p.xi), rather than on its social or environmental aspects.

> If dementia is seen as a chronic, degenerative disease for which there is no known treatment, then the logical conclusion is that nothing can be done. But if the illness is viewed as a problem with many components, some of which can be solved while others cannot, it becomes reasonable to plan interventions (Zarit, Orr, and Zarit, 1985, p.1-2).

While the search for a cure for Alzheimer's disease continues, helping patients and their families with practical questions and the development of nonbiological management techniques is very important. According to Gilhooly et al. (1986), without a cure, the identification of types of interventions which will best help the patient and family minimize the disruptive effects of the disease becomes a key issue.

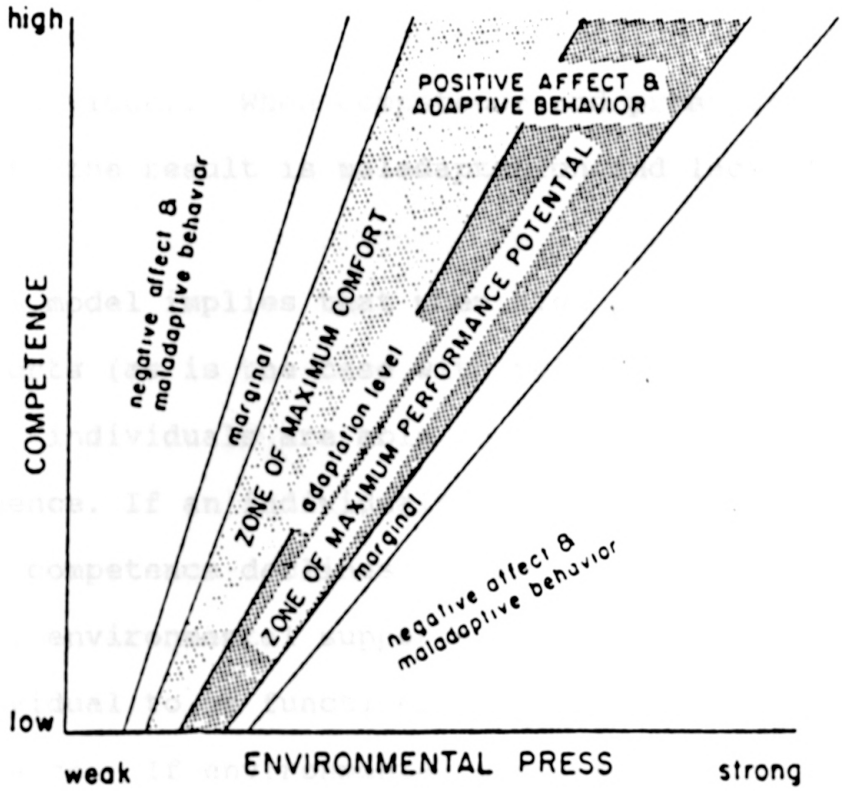
A wide variety of intervention strategies have been suggested to improve the patients' functioning. Among these strategies, the design of a sensitive, therapeutically

supportive environment may contribute to patient functioning and reduce caregiver burden (c.f. Calkins, 1988; Cohen et al., 1988; Mace and Rabins, 1981; Pynoos et al., 1988; and Pynoos et al. 1989). The case for such environmental interventions gains strength through the practical realization that the environment is a tool that is always present and often amendable to change.

The Role of the Environment in Coping with Alzheimer's Disease

Lawton and Nahemow's (1973) transactional model of competence/press provides one means for conceptualizing the relationship between people and their environments and the ways in which the environment may be used as a tool for intervention (see Figure 1). The model proposes that individual adaptive behavior and positive affect are dependent upon the balance between the demand character of the environment (press) and the individual's ability to deal with that demand (competence). Competence is defined as the individual's functional capacities in the areas of life maintenance, functional health, perception and cognition, physical self-maintenance, instrumental self-maintenance, and social role performance. Environmental press is the type of stress, challenge or demands placed on an individual which activates behavior. Press can be positive, neutral, or negative, and may be part of the physical and social

Figure 1
Competence/Press Model



Source: Lawton, M. P. and Nahemow, L. Ecology and the aging process. In C. Eisdorfer and M. P. Lawton, Eds. The pyschology of adult development and aging. Washington: American Psychological Association, 1973.

environments or the sociological environment. When competence and press are balanced, the resulting behavior is characterized as adaptive, and satisfaction is experienced by the individual. When competence and press are not congruent, the result is maladaptation and lack of positive affect.

This model implies that when high ability is matched by low supports (as is the case with relatively healthy older persons), individuals are able to maximize their independence. If an individual's ability in one or more areas of competence declines (as is typical in Alzheimer's disease), environmental supports must increase in order for the individual to be functioning at the highest level of independence. If environmental supports, on the other hand, are not increased when needed, the individual would experience too much stress and be unable to cope. In reverse, the model maintains that if environmental support is too high for the individual's ability (or too much environmental support is added in response to a small decline in competence), the individual would experience boredom, sensory deprivation or excess dependency.

The theoretical model of environmental competence/press also illustrates the "environmental docility" hypothesis (Lawton, 1970). According to this hypothesis, high competence is associated with relative independence from environmental press, while low competence is associated with

a greater vulnerability to environmental press. Put another way, a small change in press has a greater impact on the behavior of a low-competence individual than on the behavior of a high-competence individual. For example, as a person's competence decreases, external environmental factors may become more and more important determinants of behavior and affect (Lawton, 1970). Thus as the course of Alzheimer's disease progresses and the patient's competency declines, the aspects of the physical milieu may become increasingly important to assist the patient and/or reduce the difficulties in caregiving.

Kiyak used Lawton and Nahemow's (1973, 1975) competence/press model of aging as the framework of her research on Alzheimer's disease. She states that "as cognitive function and physical health deteriorate, elderly with Alzheimer's disease will experience greater incongruence and stress,..."(Kiyak, 1983, p.1). This means that ..."Older persons who are cognitively and physically intact can learn to adapt to most environmental change. But the coping skills necessary to adapt to this incongruence often deteriorate in the older person with advanced dementia" (Kiyak, 1983, p.1). This often causes further deterioration of adaptive skills in Alzheimer's patient and results in maladaptive behavior.

Thus the growing confusion, disorientation and deterioration of cognitive and physical function in the

Alzheimer's patient makes the physical environment of the home and it's adaptation more important. These models suggest that environmental interventions (modifications of the physical aspects and features of the Alzheimer's patient's living environment) can be important elements in reducing maladaptive and negative behaviors. Congruence between competence and environmental press can reduce maladaptive behaviors and, as a result, ease the burden of care.

Derived from implications of their competence/press model, Lawton and Nahemow's ecological change model classifies intervention in four ways, as shown in Figure 2. According to Lawton, Windley, and Byerts (1982), the ecological change model also provides a way to conceptualize interventions that may contribute to adaptive behavior and positive affect. These strategies can be applied to either the environment or the individual. Intervention may involve the individual as a relatively passive recipient of the intervention or as the active initiator of either environmentally or personally applied interventions. Within this framework, the present study could be described with the point of intervention as the environment and the Alzheimer's patient's role as that of a respondent to social and environmental engineering.

Figure 2
Ecological Change Model

Point of application	The Individual's role: Respondent	The Individual's role: Initiator
The environment	A Social and environmental engineering	B The individual redesigns his environment
The individual	C Rehabilitation, therapy	D Self - therapy growth

Source: Lawton, M. P. and Nahemow, L. Ecology and the aging process. In C. Eisdorfer and M. P. Lawton, Eds. The pyschology of adult development and aging. Washington: American Psycholocial Association, 1973.

The Symptoms and Stages of Alzheimer's Disease

The design of sensitive and supportive physical environments for the cognitively impaired elderly requires an understanding of the basic needs of this special population. This section provides a brief description of Alzheimer's disease, it's symptoms and progress.

Alzheimer's Disease (AD)

The classical clinical syndrome includes dementia (the "impairment in mental or intellectual function and global cognitive abilities of long duration (months to years) of gradual onset and course accompanied by neuropathological changes of the Alzheimer's type, including neurofibrillary tangles, senile plaques, and granulovacular degeneration. Alzheimer's disease, as defined, may thus become manifest either before or after 65 years of age" (Reisburg, 1983, p.5). It is "the most common form of dementia, an organic brain disease leading to progressive loss of brain function and eventual death" (Kwon, 1988, p.8). Symptoms include memory loss, loss of language function, inability to think abstractly, instability, loss of sense of time and place, and behavior problems", Kwon, 1988, p.8-9).

According to Zarit et al. (1985), Alzheimer's disease was originally described in 1907 by the German physician, Alois Alzheimer. Alzheimer's disease is a gradual progressive disorder whose stages become increasingly

severe. Eventually Alzheimer's disease affects virtually every aspect of the patient's intellectual and mental abilities. The course of dementing illness varies from one person to another, and not all Alzheimer's patients have the same symptoms. It is also common for Alzheimer's disease symptoms to vary for one individual over the course of a day, a week or years. Some clinical observation suggest that Alzheimer's disease occurring in younger persons is more severe and involves more extensive biochemical abnormalities. People diagnosed with Alzheimer's disease may live from two to twenty years after the onset of memory loss symptoms, and in rare cases even longer. On the average they live seven to nine years. The life expectancy of an Alzheimer's patient is reduced up to one third when compared to other elderly people.

Stages of Alzheimer's Disease

Because there can be considerable variation in Alzheimer's disease symptoms and their progression from patient to patient, it is difficult to clinically diagnose a patient with Alzheimer's disease. It is also difficult to outline well-defined stages of Alzheimer's disease. Therefore, various researchers divide the stages of Alzheimer's disease differently. This study employs Reisburg's (1982) classification of the progressive decline in cognitive and behavioral abilities as summarized by Zarit

et al. 1985, p.16) into the following five stages:

> In the first stage, memory deficits are observed, along with mood disturbances (anxiety, depression). As memory worsens, there is a loss of ability to perform complex activities (stage 2). Stages 3 and 4 involve increased impairment of memory and the loss of ability to function independently. Eventually, all verbal and self-care abilities are lost (stage 5).

Figure 3 provides a more complete description of Reisberg and his associate's classification of the last five progressive stages of Alzheimer's disease.

Symptoms of Alzheimer's Disease and Their Environmental Consequences

Alzheimer's disease is characterized by specific pathological changes in the brain. The most important are neurofibrillary tangles, and they occur most densely in an area of the brain associated with recent and short-term memory, known as the hippocampus (Powell and Courtice, 1986). The second pathological brain change is neuritic plaques. Plaques are masses of degenerated cell matter which occur in the spaces between cells and interfere with messages that are sent from cell to cell. Granulovacular degeneration is another type of pathological brain change. When granulovacular structures occur, the interior of the brain cells are affected.

Chemical changes can also be found in the brains of those affected with Alzheimer's disease. According to Zarit

Figure 3
Cognitive Function Scale

Alzheimer's Disease Stages

3.
- cognitive deficits apparent to intimates and associates
- patient tries to deny and hide cognitive impairments
- patient develops anxiety about symptoms
- difficulty performing in demanding work and social situations
- job performance declines
- difficulty remembering what they read or are told
- difficulty finding the right word in conversation

4.
- person does not admit to experiencing any problems
- difficulty in knowing current or recent events
- no difficulty with time orientation
- able to travel to familiar locations
- less able to handle finances and marketing
- complex tasks may be overwhelming (withdraws from challenging situation)

5.
- difficulty recalling information about major aspects of their past (address, relatives's names)
- disorientated to time or to place
- able to retain facts about themselves and close relatives (spouse, children)
- no assistance required with toileting or eating
- less able to choose proper clothing
- may need encouragement to bathe

6.
- occasional difficulty remembering spouse's name
- able to remember their own name most of the time
- able to recall some knowledge of past events
- unaware of surroundings (time and place)
- less able to travel to familiar locations (usually requiring a travel escort)
- daily activities are frequently disturbed
- progressive decline in personal hygiene (difficulty in dressing, bathing, toileting, urinary incontinence, fetal incontinence)

7.
- speech and motor abilities are minimal or lost (limited vocabulary, unable to walk)
- patient is incontinent of both urine and bowel
- requires assistance with toileting and feeding
- completely bedridden

*Source: Reisburg (1985).

et al. (1985), a deficiency in the synthesis of neurotransmitters also is believed to be one of the major reasons for the symptoms of Alzheimer's disease. The greater number of pathological changes such as neurofibrillary tangles, neuritic plaques, granulovacular degeneration, and chemical changes present in the person's brain, the more disturbed the person's intellectual functioning and memory will be. These pathological changes are of significant importance to the Alzheimer's disease patient and those who must care for them, because the loss of intellectual abilities can make the world a very confusing place for Alzheimer's disease patients. According to Powell and Courtice (1983):

> For Alzheimer's victims the loss of intellectual abilities is of sufficient severity to interfere with everyday social and occupational functioning. The victim's capacity to think abstractly is impaired; he is unable to find similarities and differences between related words and has trouble defining words and concepts (p.12).

These deficits in intellectual abilities, along with sensory impairment frequently associated with normal aging, often make it difficult for these patients to correctly interpret their environments.

Sensory overload or an increase in the complexity of demand from the environment can further antagonize these problems. Sensory overload can be caused by distractions which upset the patient, such as too many people in one room

talking or moving around, or from music and other extraneous background or undefined noises occurring at the same time. Controlling extraneous noises has important environmental implications such as the use of acoustical materials or the reduction of noise from machines and appliances.

Persons suffering from Alzheimer's disease may become disorientated in respect to people, places and time. According to the American Association of Homes for the Aging (1985), there are subtle ways in which the environment can help provide the patient with a sense of reality. For example, they suggest that clocks and calendars present in the home may help patients with orientation to time, and that clear differentiation of locations within the home may assist residents with orientation to place.

The Alzheimer's disease patient's judgment also is impaired. Impaired judgment caused by brain disturbances can affect many areas of a person's life and may have dangerous consequences. Driving, cooking, shaving, and taking medicine are a few activities where poor judgment may become evident as well as dangerous. Environmental interventions such as hiding the car keys, or disengaging the spark plugs of a vehicle may be necessary to prevent the patient from driving. The knobs on cooking appliances may have to be removed or camouflaged to protect them from accidents. Razor blades and medications may also have to be locked in a cabinet or closet to prevent the judgment

impaired person from getting into them without assistance.

The severity of brain disturbances are also affected by how the patient copes with Alzheimer's disease. Reducing environmental press by providing a familiar, well-organized and comfortable environment may help to minimize these types of problems. These disturbances may also include impairment in the person's use of language (aphasia). According to Gruetzner (1988), environmental interventions such as a sign on the bathroom door may help the patient point to or locate the bathroom. Posters or notes can be used to remind individuals, in the early stages of the disease, of important names and numbers.

Apraxia, which is the inability to complete motor activities, also may be a symptom of Alzheimer's disease. A clean, uncluttered, and easily negotiable environment, along with the use of handrails, grab-bars, and ramps may assist people with this problem. Agnosia is another brain disturbance which is described by Powell and Courtice (1983), as the "failure to recognize or identify objects despite intact sensory and motor functions of the brain" (p.12). They give the example that a person with agnosia may see a mantlepiece, but might walk into it anyway. This is because the person does not always fully understand what it is that is seen. As a result, the person does not correctly recognize that it is protruding from the wall. Environmental modifications, such as blocking off stairs and

removing furniture and accessories, may help prevent accidents related to agnosia.

Difficult behaviors often accompany the loss of intellectual functioning. As people with Alzheimer's disease become more unsure of their surroundings and what is expected of them, they become more dependent on their caregivers and the environment for reassurance and security. Sometimes there may be events or factors in the environment which triggers a problem behavior. Therefore, it is important for the caregiver to understand what is happening to the person with Alzheimer's disease and to consider how the environment affects the person's behavior, as well as his or her own ease of caregiving when planning interventions.

Design Criteria Suggested for Environments for People with Alzheimer's Disease

In a recent body of work Cohen et al. (1988) presented a set of seven design principles (therapeutic guidelines) which provide a basis for the planning, programming, and design of environments suited for people with dementia. Cohen and Weisman (in press) in their most recent work, divided the goal of privacy and control into separate goals and added the goal of fostering social interaction and support. Their guidelines are not limited to one type of environment, but can be applied to a wide range of

residential and institutional settings. These guidelines were based on research literature, a series of case studies, analyses of existing facilities, and interviews with experts in the field. The seven therapeutic goals include:

1. Safety and security
2. Support functional abilities
3. Awareness and orientation
4. Stimulation and challenge
5. Privacy and control
6. Adapt to changing needs
7. The healthy and familiar

(See Appendix A for a more detailed list of these seven therapeutic goals.)

Pynoos et al. (1988), developed a similar set of suggestions to guide and help caregivers to manage the behaviors that often accompany Alzheimer's disease by providing caregivers with coping strategies and an inventory of potential environmental modifications. They suggest that the Alzheimer's disease patient's environment should be designed to:

1. Promote dignity and independent functioning.
2. Provide appropriate sensory stimulation.
3. Provide security and safety for the individual.
4. Provide appropriate level of activity/task.
5. Provide a homelike and familiar atmosphere.
6. Provide for individual control and privacy.
7. Create opportunity for socializing.
8. Be flexible and adaptable in supporting the person's behavior and physical needs.
9. Emphasize wellness and maintain connection with the healthy and familiar.

In order for the patient's environment to meet these criteria, Pynoos et al. (1988) suggest the following strategies for environmental management:

1. Removing or modifying objects
2. Enriching home like environment and increasing familiarity
3. Restricting or changing an area
4. Introducing environmental modifications
5. Simplifying tasks and the environment
6. Providing appropriate environmental and sensory stimulation
7. Diverting attention

(See Appendix B for a more detailed list of these environmental management strategies.) These and many other suggestions given in their book can be applied to a variety of settings.

The Long Term Care National Resource Center at UCLA/USC also has developed a Home Modification Resource Guide (1989) to assist organizations and others concerned with keeping frail older persons in their homes and preventing unnecessary institutionalization in locating helpful information. This booklet does not describe specific environmental interventions but it offers valuable information about the resources available concerning a variety of topics concerning adaptations to the home environments of functionally impaired individuals.

Homecare of Persons with Alzheimer's Disease

Despite the identification of Alzheimer's disease as "the major cause of institutionalization among the more than one million persons in nursing homes in the United States alone" Reisberg (1983), a majority, perhaps two-thirds, of afflicted persons with severe Alzheimer's disease probably

continue to be cared for in their homes (Kwon, 1988; Reisburg, 1983). According to Gilhooly et al. (1986), the ability of these individuals to remain in the community usually depends on the availability of a family member (typically a spouse or daughter) or other caregiver. However, because Alzheimer's disease patients often require a considerable amount of supervision, the care of these patients can become overwhelming. There are no clear cut management approaches for dealing with elderly patients with Alzheimer's disease living at home. Caregivers of these patients are often faced with unique problems because the patients suffer severe declines in intellectual functioning, self-care behaviors, personality, and other behaviors. As a result, the caregivers often experience high levels of stress. Not only do these caregivers vary in the amount of stress which they experience, but they also vary in their ability to cope successfully with stressors.

Noelker's (1982) study makes an empirical connection between stress effects experienced by caregivers and various environmental barriers in the home setting. These data documented that environmental barriers within the home environment present obstacles for the caregiver caring for impaired elderly relatives at home and are associated with various types of care-related stress.

Significant correlations were found between the total number of care-related stress effects and the total number

of home barriers (r=.14). There were also significant positive correlations between the total number of care-related stress effects and difficulties with mobility (r=.14) and toileting aids (r=.14). Multiple regressions predicting the care-related family disruption and the negative changes in caregivers' health were employed to assess the relative importance of various barriers (such as insufficient storage space, bedrooms and bathrooms, and the need for grab bars) in relation to care-related stress effects. In both cases, the number of spatial barriers accounted for 4% of the variance and were statistically significant (p=.001).

Caregivers cope with the stress associated with caregiving in different ways. Coping is defined by Stone and Neale (1984) as "those behaviors and thoughts which are consciously used by an individual to handle or control the effects of anticipating or experiencing a stressful situation" (p. 893). The outcome of any stress depends on many factors: the nature of the stressor (type, frequency, duration, and intensity); the person's appraisal of the stressor (as a threat or challenge); and the resources at his or her disposal (e.g.,social support, problem-solving abilities).

High levels of stress and maladaptive behavior often result from a mismatch between the people's perceived demands on their lives and the competence that they believe

themselves to have. The amount of stress the caregiver of an Alzheimer's disease patient perceives may be influenced by the severity of the patient's cognitive impairment, behavioral problems, and disabilities in self-care. According to Stone and Neale (1984) how the caregiver psychologically appraises the situation may be influenced by the control they perceive in handling the problems, and how bothersome they perceive the problem or behavior to be. Thus, their appraisal of how distressing a problem is, and their effectiveness in managing problems (such as problem solving skills and abilities to make changes) are likely to mediate between the stressors, including environmental problems, and caregiver outcomes.

Thus, the prevention or delay in putting an Alzheimer's disease patient in a nursing home is a realistic possibility for many families. Early and appropriate intervention directed to helping families manage the stresses of caregiving more effectively may make home care a more viable alternative for a longer time. Such interventions may have some affect on the number of persons admitted to nursing homes, but more importantly, they may help individuals and families who would be providing care at home to provide better care.

Purpose and Objectives of the Study

The purpose of this study is to examine the ways in

which caregivers of patients with Alzheimer's disease cope with the cognitive and behavioral problems which might respond to environmental intervention or management, and the role that environmental interventions and solutions actually play in the caregiver's coping strategies. Descriptions of the use and effectiveness of such interventions, and their relationships to the stress and control perceived by caregivers, can provide an empirical basis for environmental interventions to be used by designers and caregivers to reduce the burden of care.

The objectives of this study are:

1. To describe for specific cognitive and behavioral problems associated with the long term care of Alzheimer's patients in the home environment:
   (a) their frequency,
   (b) the level of stress caregivers perceived,
   (c) how caregivers coped with environmental stressors related to these problems, and
   (d) the relative importance and effectiveness of environmental interventions and solutions in the caregivers' repertoires of coping strategies.
2. To describe at different degenerative stages of the disease:
   a. What cognitive and behavioral problems occurred which might respond to environmental

intervention or management, and how frequently they occurred.

b. When each of these problems occurred, to describe how stressful it was to the caregiver, how much control the caregiver perceived over solutions to the problem, and what types of coping strategies the caregiver used.

c. To describe which of the environmental solutions to behavioral problems the caregivers perceived as the most effective.

3. To explore what role interventions in the physical environment play in the stress and control perceived by the caregivers of Alzheimer's patients.

   a. across all problems

   b. for each cognitive and behavior problem

4. To explore relationships between characteristics of the caregiver, the environment, and the frequency of the use of environmental management strategies by caregivers.

5. To suggest to future caregivers, problem-focused interventions which may reduce environmental stressors in the home environments of Alzheimer's patients.

CHAPTER TWO

METHOD

This chapter describes the selection of respondents and the procedures and instruments that have been used to gather and evaluate information necessary to meet the objectives of this study.

Sample

The family caregivers of 30 elderly persons with Alzheimer's disease were recruited from a variety of sources. These sources included caregiver support groups in Manhattan, Kansas, Topeka, Kansas and surrounding areas, referrals from other caregivers, physicians, social workers, home care personnel, friends, and the closest chapters of ADRDA (The Alzheimer's Disease and Related Disorders Association). The 30 caregivers interviewed for this study were from seven different towns located in Kansas and Nebraska.

Criteria for Selecting Caregivers

A telephone screening interview was used to assure that all respondents were primary caregivers for an elderly person with Alzheimer's disease. (See Appendix C for the complete list of the telephone interview questions.) As a

primary caregiver, the respondent had to describe him or herself as being responsible for at least 50% of the patient's care. Only one caregiver from each family was interviewed, and that caregiver was only interviewed in connection with one impaired relative. The caregiver of the Alzheimer's disease patient had to reside in the same residence as the patient or the patient must have lived within the home in the last two months. In a few cases, the caregiver lived within one block of the patient so that close contact and surveillance were possible. In these situations the caregivers were responsible for the care and upkeep of the second property and the patient. The caregiver also had to have reasonable control of the patient's environment so that he or she was able to implement environmental interventions, if desired. The caregiver had to describe the elderly patient as having at least a six-month history of memory impairment suggestive of Alzheimer's disease, and have had a medical diagnosis consistent with Alzheimer's disease.

There were 33 caregivers contacted by the researcher who met the criteria for this study; of those, 30 or 91% of them agreed to be interviewed.

Characteristics of the Caregiver

An overwhelming majority of the 30 caregivers interviewed (n=28) were caucasian. The race of the

remaining caregivers (n=1) was evenly distributed between black and hispanic. A high percentage of primary caregivers (n=25) were female and a much smaller percentage (n=5) were male. Table 1 displays the ages of the caregivers. The mean age for female caregivers was 61.2 years with ages ranging from 29 to 91, while the mean age for male caregivers was slightly lower at 58.6 years with ages ranging from 40 to 76.

Table 2, describing the relationship of the caregiver to the patient, shows that most often the primary caregiver was the patient's spouse. More than half (n=17) of the primary caregivers were the husband or wife of the patient. The second most frequent caregiver was a daughter (n=8) of the patient. Sons, daughters-in-law, and outside caregivers were also involved as the primary caregiver of these patients. Table 2 also suggests that if the patient was a male, the primary caregiver typically was a spouse. However, if the patient was a female, over half of the time (n=8) the primary caregiver was a daughter rather than a spouse (n=3).

Table 3 describes the characteristics of the caregivers. As Table 3 indicates, almost all the caregivers (n=29) were married. The one remaining (n=1) was divorced. Many of these caregivers (n=12) were homemakers. The employment status of the remaining caregivers was distributed almost evenly between retirement (n=7), full

Table 1

Age of Caregivers

	Male Patients	Female Patients	All Caregivers
M	58.6	61.2	60.8
SD	15.4	13.4	13.5
RANGE	40-76	29-91	29-91

n=30

Table 2

Relationship of Patient to Primary Caregiver

	Male Patients	Female Patients	All Patients
Spouse	82% (n=14)	23% (n=3)	57% (n=17)
Daughter	0% (n=0)	62% (n=8)	27% (n=8)
Son	6% (n=1)	8% (n=1)	7% (n=2)
Dau-in-law	6% (n=1)	8% (n=1)	7% (n=2)
Non Family: (Female)	6% (n=1)	0% (n=0)	3% (n=1)

n=30

Table 3
Distribution of Caregiver Characteristics

		Percentage	
Marital Status	Married	93%	(n=28)
	Divoraced	7%	(n=2)
	Single	0%	(n=0)
	Widowed	0%	(n=0)
Employment	Part-time	20%	(n=6)
	Fulltime	17%	(n=5)
	Retired	23%	(n=7)
	Homemaker	40%	(n=12)
Education	Below High school	13%	(n=4)
	High school	23%	(n=7)
	Tech/Jr College	40%	(n=12)
	4 Yr Grad & Above	23%	(n=7)

n=30

-time employment (n=5), and part-time employment (n=6). A large majority (n=26) of caregivers had graduated from high school (see Table 3). Of those who graduated from high school, all but seven caregivers also attended college or a technical school for a minimum of one to three years.

The characteristics of the housing reported by caregivers are summarized in Table 4. In a large majority of cases (n=26), the home was owned by the patient or caregiver. A few caregivers and patients (n=4) rented their homes. Whether they owned or rented the property, the most frequent dwelling type in the sample was a single family house (n=26). Other types of housing included an apartment, a duplex, a triplex, and a mobile home.

Most of the houses (n=24) had one or two levels, and of those, over half (n=16) had two levels. Most of the two level homes (n=14) had a basement, and all (n=6) of the homes with more than two levels had basements. Most of the basements were unfinished, and used only for storage and/or as a laundry area. Many of the homes sampled in this study seemed to have one primary level for daily living for the patient with Alzheimer's disease. This meant that a bathroom, kitchen, living room and bedroom usually were found on one floor of the home. A home where it was possible to care for someone on one level may have been a deciding factor in whether to try to care for the patient with Alzheimer's disease at home.

Table 4

Housing Characteristics

		Percentage	
Ownership	Rent	13%	(n=4)
	Own	87%	(n=26)
House type	Single Family	87%	(n=26)
	Apartment	3%	(n=1)
	Duplex	3%	(n=1)
	Triplex	3%	(n=10
	Trailer	3%	(n=1)
Number of Levels	1	27%	(n=8)
	2	53%	(n=16)
	2.5	3%	(n=1)
	3	13%	(n=4)
	5	3%	(n=1)

n=30

Thus, the modal caregiver was a caucasian female with the mean age of 60.8 years. This caregiver was a married homemaker who had attended college or technical school forone to three years. The caregiver was caring for a spouse in a two story single family home with a basement. This caregiver also owned the home, and had lived there an average of 17.4 years (range of 0 to 41 years).

Procedure

Most of the caregivers of these patients were initially contacted by a letter from the researcher which described the study and included informed consent information (see Appendix D). Other caregivers were initially contacted by personnel in a physician's office, a fellow caregiver, or by one of their friends, and were asked for permission for the researcher to contact them. Next, the caregivers were contacted to participate in the telephone screening interview. At that time, if the potential respondent met the criteria for the study, an interview appointment was arranged. The assessments usually took place in the caregiver/patient's home. At times when an interview in the home would have been difficult for the caregiver or might have upset the patient, the interview was conducted in a neutral place such as a restaurant or respondent's office. Each caregiver was asked to complete a series of structured questions in the interview. These questions included

background information about the caregiver and the patient. In addition, a camera was used to document environmental interventions. The interviewing process for all respondents was completed in August, 1989. (See Appendix E for the complete questionnaire.)

Measures

Background Information Questionnaire

This instrument was used to collect basic demographic and descriptive information about the patient with Alzheimer's disease, the caregiver, and the home environment (eg., race, age, sex, housing type).

Assessment of Cognitive and Functional Characteristics of Patients

Adaptations of the criteria from Reisburg's Cognitive Function Scale (1983) and adaptations of Lawton and Brody's Physical Self-Maintenance Scale (1969) were used to assess the severity of the patient's cognitive, behavioral and self-care impairment, as perceived by the caregiver.

Adapted Cognitive Function Scale

The number of stages in Reisburg's Cognitive Function Scale (1983) included in this study was five, rather than seven. The first and second stages in Reisburg's scale

describe normal behavior to slight memory loss which is often not evident to people near the patient, and people in these stages often are not diagnosed as having Alzheimer's disease. The memory and behavior problems included in this study begin to surface in Reisburg's third stage. Therefore, patients in the first two stages were excluded from the study. The clinical characteristics, and particularly the observable behaviors describing each of Reisburg's stages were summarized for the caregiver by the researcher so that the caregiver could more easily distinguish the stage that best described the patient's current's condition. The caregivers were then asked to locate on the adapted list of Reisburg's Cognitive Function Scale what stage of Alzheimer's disease best described the relative's current condition.

Adapted Physical Self-Maintenance Scale

The Physical Self-Maintenance Scale (PSMS) is a short interview instrument which assesses the ability to manage fundamental self-care behaviors in the following six areas: toileting, feeding, dressing, grooming, physical ambulation and bathing oneself. The Physical Self-Maintenance Scale (PSMS) used in this study was originally developed at the Langley-Porter Neuropsychiatric Institute by Simon, Lowenthal, and their associates in 1964. Since then, it has been used by many different investigators, including Lawton

and Brody, whose adapted scale has met appropriate Guttman scaling criteria (Lawton and Brody, 1969). In completing this scale, the caregivers had to chose among five statements that described the progressive decline in self-care abilities associated with the declining stages of Alzheimer's disease. (See Appendix F for Lawton and Brody's adapted scale.)

Lawton and Brody's Physical Self-Maintenance scale was adapted to meet the needs of the present study because the scale includes measures to evaluate an individual's physical ambulation in the areas surrounding their home. This study focused on the home environment because most patients in the later stages of Alzheimer's disease have great difficulty negotiating outside their homes without assistance. Therefore, the expectations in the level of ability of physical ambulation were lowered from the Lawton and Brody scale in attempt to better measure the level of physical ambulation for patients in this study.

The adapted Physical Self-Maintenance Scale (PSMS) was used in this study to give each patient two scores measuring the ability to manage self-care in the six areas. In each area, the caregiver was asked to choose which of the five statements best described the patient's current self-care ability. The statements describing the patients abilities ranged from high functioning to low functioning.

The first score generated by this assessment (PSMS1)

was based on the same rating score employed by Lawton and Brody. They awarded the patient "1" point if the caregiver described the patient as being in the highest functioning category and "0" if the patient was described at any other point on the scale. Thus PSMS1 scores could range from 0 to 6 points, and are comparable to those obtained by other researchers using the Physical Self-Maintenance Scale.

Because many Alzheimer's disease patients have difficulty in several of these areas, their scores typically would be low and would show little variation. For example, a patient who might need only minor assistance could receive the same score as a patient who needs extensive assistance. In order to obtain a more precise measurement of each patient's limitations, each individual was given a second score (PSMS2) based on the full range of functioning described by the scale. Patients described by their caregiver to be in the highest functioning category received "5" points for that activity, and as the ability declined, so did the number of points awarded on a five point scale. Low functioning for a particular activity was awarded "1" point. Thus the PSMS2 scores could range from 6 to 30.

Memory and Behavior Problem Checklist Assessed

Items selected from the Memory and Behavior Checklist and Physical Self-Maintenance Scale were employed to explore the problems and environmental solutions involved in caring

for Alzheimer's disease patients in the home. The Memory and Behavior Problem Checklist was developed by Zarit and his colleagues (Zarit and Zarit, 1982; and Zarit et al. 1985) to identify the occurrence and frequency of everyday problems associated with senile dementia (see Appendix G for a complete list of Memory and Behavior Problems). The information obtained through this instrument functionally analyzes behavioral problems. A modified version of the Memory and Behavioral Problem Checklist (MBPC) was used in this study to identify and assess the severity of each patient's behavioral problems. The problems chosen from the Memory and Behavior Checklist are those for which environmental interventions could be used as partial or whole solutions. These include the first nine items from Zarit and his associates' checklist (wandering, hiding things, losing or misplacing things, forgetting what day it is, destroying property, waking up at night, engaging in behavior potentially dangerous to others, engaging in behaviors potentially dangerous to self, and seeing or hearing things that are not there), plus the last option, "other", for memory and behavior problems not on the list. The wording of five other items from their list was modified, and two items were added in order to incorporate the six items listed on Lawton and Brody's Physical Self-Maintenance Scale. A brief description of the problem behaviors, the rationale for the selection of these

particular scale items, and some of the common environmental interventions employed follows.

Wandering

Wandering is the first problem listed on the Memory and Behavior Problem Checklist, and has been recognized as one of the most common behavior problems related to the Alzheimer's disease patients' safety and security. As the persons' judgments become increasingly impaired they become more disoriented. The more disoriented they become, the more likely they are to be a danger to themselves. This danger is dramatically increased when the person wanders away from home. There are many environmental interventions which caregivers can apply to help handle this problem suggested by Cohen and his associates (1988), Peppard (1986), and Pynoos and his associates (1988). These strategies include locking the doors and windows, the use of alarm systems, and fencing in the yard and securing gates. Kwon suggests that "selected doors may be 'disguised' so that patients do not try to use them" or "half doors or dutch-doors may be used in some interiors to discourage entry or exit but allow surveillance" (1987, p. 33-34).

Hiding, Losing, or Misplacing Things

Alzheimer's disease patients often hide, lose, and misplace things. Usually the Alzheimer's disease patient

either puts things down and forgets where he/she puts them or hides them so well that no one can find them. Suspicious and paranoid behaviors are often associated with hiding, losing, and misplacing items. This is because Alzheimer's disease patients live in a very confusing world where things seem to disappear without explanation. When they can't find something, they assume this item has been stolen.

There are many environmental interventions offered by Pynoos and his associates (1988) which can help reduce this problem. Mace and Rabins (1981) also suggest that keeping a clean house will make it easier to locate lost items. Small frequently misplaced items may be easier to find if they are made larger and/or more visible. They also suggest limiting the number of hiding places by locking closets and doors.

Forgetting What Day It Is

When memory fades, the judgment which allows us to measure the passage of time also fades. Alzheimer's disease often affects the internal clock which helps the person keep track of time. The environment can provide cues and information about the passage of time, as suggested by Cohen et al. (1988), and Pynoos et al. (1988). According to Mace and Rabins (1981), having clocks and calendars in view may help the person with time orientation, and marking off the days as they pass may help the impaired person remember what day it is.

Waking the Caregiver Up at Night

People with Alzheimer's disease are often restless at night. Wandering may occur when the person awakes in the middle of the night and then forgets the reason for waking up. In addition, many older people do not see well in the dark, and this limitation may add to their confusion. Robinson, Spencer, White, and Kilbourn (1988), suggest that providing night lights in the bedroom, bathrooms, and other rooms may cut down on the person's confusion during the night and may also help the person find the bathroom. They also recommend adding bedrails to remind the person that he or she is in bed. Mace and Rabins (1981) suggest making sure the person's sleeping arrangements are comfortable, since the person may awaken if the bed is uncomfortable or he/she is too hot or too cold.

Destroying Property, Engaging in Behaviors Potentially Dangerous to Others or to Self

As Alzheimer's disease progresses, patients become less aware of the dangers in the environment to themselves and to others. The more impaired the person becomes, the more likely situations in the environment will overwhelm them. According to Cohen et al. (1988), as the disease progresses, individuals may not be able to handle high levels of stimulation without experiencing increased stress. These researchers feel that it is essential to regulate the amount

of environmental stimulation in the person's environment in order to match the person's changing abilities. Too much stimulation in the environment may cause the impaired person to overreact and destroy property or engage in behaviors which may be harmful to self or others.

According to Pynoos et al. (1988), to help reduce overreaction or aggressive behavior, the caregiver should simplify tasks and activities, or reduce environmental stimulation. If necessary, the caregiver should remove the person to another room which is free from other people and unnecessary noises. To prevent the person from engaging in destructive or dangerous behaviors, Pynoos and his associates recommend that caregivers remove hazardous materials or objects from the environment such as weapons, knives, poisons or other dangerous materials. Unstable furniture or furniture with sharp corners and large areas of glass, such as china cabinets and sliding doors, may have to be removed or blocked off.

Seeing or Hearing Things That Are Not There

Another problem for patients with Alzheimer's disease may occur when the person sees or hears things that are not there in reality. For example, Alzheimer's disease patients may try to pick the spots off the floor or walls or they may become agitated if they perceive the pattern on the drapes as imaginary bugs. Environmental interventions such as

trying to avoid busy patterns on floors, walls and drapes may be helpful (Peppard, 1986). Peppard also suggests that "stripes, plaids and patterns that 'dance' before the eyes should be avoided..." because she feels "...they can cause confusion and contribute to behavioral problems" (1986, p.16). Pynoos and his associates (1988), and Robinson and her associates (1988) also suggest environmental interventions for handling this problem.

Difficulty in Doing Simple Tasks

People with Alzheimer's disease forget things quickly, and as a result, they often have difficulty completing tasks. This problem may occur in situations when a task, such as taking a bath or brushing one's teeth, become too complex because of the many steps involved. Grutzner (1988) suggests that breaking a task down into smaller steps may be effective in helping the person complete complicated tasks. In addition, posting reminders and memory lists or maintaining a routine for daily activities may be helpful (Mace and Rabins, 1981; and Pynoos et al., 1988).

Difficulty in Dressing Self

As the disease progresses, the person may have difficulty dressing him or herself. Getting dressed can be a complicated task, but it can be made easier by simplifying the environment and the number of choices (Calkins, 1988;

and Pynoos et al., 1988). First, a clean uncluttered bedroom may help reduce distractions. Robinson et al. (1988), recommend putting away rarely worn clothes and out-of-season clothes to make the selection of clothing easier. Also, in the early phases of the disease, labeling dresser drawers according to content may help the confused person locate certain items.

Difficulty in Feeding Self

Difficulty in eating behaviors often accompany the progressive stages of Alzheimer's disease. Persons with Alzheimer's disease may become malnourished because they forget to eat, or they may eat continually because they forget that they have just eaten. According to Pynoos et al. (1988), changes in eating behavior may result from a lack of interest in food or from difficulty in handling the mechanics of eating, chewing, and swallowing. A caregiver may try to reduce noise and other distractions during meal times. Robinson et al. (1988), suggest that in large families, the caregiver may consider serving the confused person at a time when there is less activity. Distractions on the table itself can also be reduced by cleaning unnecessary items from the table and by avoiding patterned placemats, plates, and tablecloths, and by only setting the utensils that are needed. Dishes and tablecloths which contrast in color make the dishes easier to distinguish from

their background.

Difficulty in Toileting Self

In the more advanced stages of Alzheimer's disease, the ability to use the toilet properly often is affected. These people may begin to wet themselves or have bowel movements in their clothing or may urinate or defecate in inappropriate places. These problems occur for many reasons. The person may be less aware of the need to relieve him or herself, and in addition, memory and perceptual problems may make it difficult for the person to find the bathroom. Mace and Rabins (1981), suggest that increasing the visibility of the bathroom (by painting the door a bright color) or giving the door a different design treatment from other doors (such as a canopy) may differentiate the bathroom door from other doors and make it easier to find. If the bathroom is difficult to get to or is too far away, the person may have the problem of getting to the bathroom on time. If this is the problem, a portable commode can be placed near the person. At other times, a person with Alzheimer's disease may become confused and may not associate the bathroom with the need to relieve him or herself, or may not remember what to do once in the bathroom. Pynoos et al. (1988) suggest trying a brightly colored toilet seat or removing the toilet seat cover to call attention to the toilet. In the early stages of the

disease, a sign placed next to the toilet may also be helpful in reminding the person of the steps involved in toileting. Calkins (1988) and Robinson and her associates (1988) also offer suggestions for environmental modifications.

In Noelker's (1982) study, which included both physically and mentally impaired individuals and their caregivers, one of the navigational barriers she identified in the home environments of elderly impaired residents was bathroom fixtures. Almost half of the caregivers in her study reported that bathroom fixtures were hard for the elder to use. She documented that care-related stress effects were significantly related to the patient's difficultly using bathroom fixtures and the elderly impaired person's difficulty using toileting aids. She also found that toileting aids had unexpectedly low use despite the fact that over half of the elders in her study had difficulty with continence.

Difficulty in Bathing and Grooming Self

Persons with Alzheimer's disease often have difficulty in bathing and maintaining their personal hygiene. Problems in these areas may arise because the person loses interest in these activities or forgets their social importance. According to Pynoos et al. (1988), the person's resistance to bathing may come from embarrassment, fear of water, fear

of getting in or out of bathtub, or the inability to remember how long it has been since the last bath. Robinson et al. (1988) suggest that pulling down the blinds and closing the bathroom curtains and doors may help to create a feeling of privacy. The fear of bathing can be related the person's forgetting how to adjust the water temperature or how to use the soap or washcloth. The caregiver may adjust the setting on the water heater to keep the person from scalding him or herself. The caregiver also may try to simplify the task by laying out the soap, washcloth, towel, and clean clothes in the correct sequence and/or by instructing the person through each step (Pynoos et al. 1988). As the person's coordination becomes more impaired, he or she may become afraid of falling. Letting the water drain before the person steps out of the tub, and employing the use of assistive devices may be helpful. Caregivers in Noelker's research (1982) reported a need for railings and grab bars, and Robinson et al. (1988) suggest that grab bars which help the person get in or out of tub, non-slip bathmats and decals, and adjustable safety benches or bath chairs may make the person feel more secure. A bath chart or calendar can be used to show the person when he or she last took a bath.

Difficulty in Moving Around Within the Residence

Elderly persons with Alzheimer's disease not only have

to deal with problems related to the disease, but also with problems associated with the normal aging process. Decreases in strength, muscle fiber, grip, mobility, balance, and reaction time often make it difficult for the person to move around within the residence. In Noelker's study (1982) she reported that mobility aids such as canes, walkers, and wheelchairs were frequently used, and that the elderly's difficulty with mobility aids contributed significantly to the caregiver's stress-effects. As the person becomes more confused, even a home that has been lived in for many years may become hard to negotiate. According to Gidley (1985), it may help to keep a person's belongings in view where he or she can see them, and to put items back in the same place. Pynoos et al. (1988), suggest that a clean, uncluttered environment with rugs and carpet that are securely fastened down, the use of stable furniture, clear circulation paths, and the removal of low furniture (such as step stools and small coffee tables) may help prevent accidents.

Frequency of Memory and Behavior Problems

During the caregiver interview, caregivers were first asked how frequently in the past week a particular problem had occurred. The multiple choice answers offered to the caregivers included the following:

a. never occurred
b. has occurred, but not in the past week

c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurred daily or more often
f. would occur if not supervised by caregivers (e.g. wandering except the door is locked)

Caregivers were asked about the frequency of each of the 16 memory and behavior problems. The response "would occur if not supervised by caregiver" was offered but was never reported by the caregivers.

Caregiving Stress

In order to measure the caregiver's psychological appraisal of each of the problems identified above, two questions were asked in relation to each item in the caregiver interview. First, if the problem had occurred, the caregiver was asked to rate how stressful that problem was on a scale from 1 to 10. A score of "10" would be equivalent to the death of a friend or relative and a score of "1" would be equivalent to a minor annoyance. If the memory or behavior problem wasn't a problem for a particular caregiver, the caregiver received a score of "0". The stress scores from all of the 16 memory and behavior problems which applied to each caregiver were complied into a composite score.

Caregiving Control

Second, the caregiver was then asked about how much control he or she felt in handling that particular problem.

The response options offered to caregivers included:

a. quite a lot/complete
b. some
c. none

Caregiver Coping

How the caregiver caring for someone with Alzheimer's disease psychologically appraises the situation is likely to affect the ways and the frequency of use of coping behaviors and thoughts (Stone and Neale, 1984). Stone and Neale (1984) have developed an eight category measure of coping with daily problems based on extensive coping strategies (see Appendix H). Stone and Neale's eight coping categories, with the addition of a category of environmental intervention (which would have been included within one of their eight) was used in this study to assess how the caregivers appraised the problems adapted from the Memory and Behavior Problem Checklist. The category "environmental intervention" was added in order to directly assess the type and frequency of the use of environmental interventions (modifications) that caregivers use when trying to handle or solve these common problems associated with caring for Alzheimer's disease patients. The caregivers also were offered a tenth category "other" for items that did not fit into any other category.

After the caregiver had reported the occurrence and frequency of each memory and behavior problems, the amount

of control felt over these situations, and how stressful the problem was perceived to be, the caregiver was asked how he or she had handled (coped) with the problem. Stone and Neale (1984) recommend that the term "handled" be used instead of "coping" because it has successful connotations for many people. In order to measure how the caregiver handled the problems, the caregiver was given a sheet with the nine coping categories and their definitions written on it. After the caregiver became familiar with the definitions, he or she was asked to indicate which of the coping strategies that had been used to handle each of the problems adapted from the Memory and Behavior Problem Checklist. There was no limit on the number of coping categories the caregivers could choose for each problem.

Environmental Coping

After the caregivers had indicated which coping strategies they had employed for each of the problems they had confronted, a second series of questions were asked. If environmental intervention had been used to handle a particular problem, the caregivers were then asked to describe the environmental solution(s) they tried and whether or not each environmental solution was working.

Analyses

Descriptive statistics were used primarily in the

analyses, since this study was exploratory. In addition to analyses employing the entire sample, the caregivers' responses were divided by the different stages of the patients' disease. The problem behaviors were rank ordered to analyze which coping strategies caregivers used at each stage of the disease, and which physical environmental strategies were perceived as effective. In addition to the relative frequency of responses, Kruskal-Wallis tests (a nonparametric alternative to the one-way analysis of variance) were used to analyze the differences in problem frequency, stress, control, and environmental management (i.e., the proportion of environmental strategies used in relation to all other coping strategies) between stages. Environmental effectiveness (the proportion of environmental interventions employed by caregivers that were reported to have been successful) also was examined.

A series of regression analyses, t-tests, and correlations were used to examine the role of the physical environment versus other coping strategies employed by caregivers. More specifically, these analyses explored the relationships between (a) the occurrence of problem behaviors and the caregivers' uses of coping strategies, (b) the caregivers' perceived control and the stress related to the problems, (c) and the caregivers' perceived control over these situations and the coping strategies which they chose to employ. In addition, the role of the differences of

characteristics of the caregiver's home environments and their personal characteristics were explored in relation to environmental coping.

This study did not evaluate with this sample the reliability or validity of the measures employed. However, previous research has established the validity of these measures (Lawton and Brody, 1969; Zarit and Zarit, 1982; Zarit et al., 1985)

CHAPTER THREE

DISTRIBUTIONS OF PROBLEM BEHAVIORS, STRESS, CONTROL, AND ENVIRONMENTAL COPING

The analyses employed in this chapter examine the characteristics of the patients for whom care was provided, the frequency of problems behaviors, the amount of stress experienced by caregivers, the amount of control perceived by caregivers, and the use of environmental interventions in coping across all individuals and across all problems.

Cognitive and Functional Characteristics of the Patient

The caregivers in this sample provided care for male patients in 57% (n=17) of the cases. The distribution of patients' race was the same as that for caregivers. Most of the patients were caucasian (n=28) while the remaining (n=1) were black or Hispanic.

Table 5 shows the ages of the patients and the length of time they had experienced symptoms of Alzheimer's disease. The mean age for male patients was 75.7 years, with ages ranging from 64 to 93, while the mean age for female patients was higher, 79.3 years, with ages ranging from 61 to 94. The male patients had been suffering from Alzheimer's disease a mean of 7.6, years while the average female patient had been suffering from Alzheimer's disease a

Table 5

Percentage of Patients in Each Stage of Alzheimer's Disease

	Male Patients	Female Patients	All Patients
Stage			
4	6% (n=1)	8% (n=1)	12% (n=2)
5	29% (n=5)	31% (n=5)	33% (n=10)
6	53% (n=9)	31% (n=4)	43% (n=13)
7	12% (n=2)	23% (n=3)	17% (n=5)

n=30

little longer. Caregivers of female patients estimated that the average female patient had had Alzheimer's disease 8.3 years.

Table 6 displays the stage of Alzheimer's disease in which the caregiver perceived the patient to be. No one described the patient to be in the third stage of Alzheimer's disease and only a small number of the patients (n=2) were in the fourth stage of Alzheimer's disease. The majority fell in stages five and six, with a few (n=5) in the seventh stage as defined by the adapted Reisberg scale.

Patients had a mean PSMS1 score of 1.9 (ranging from 0 to 6), while the mean PSMS2 score was 19.5 with scores ranging from 7 to 30 (see Table 7). Table 7 also shows that female patients had an higher average PSMS1 score (1.9) than male patients (1.8). However, female patients had a lower average PSMS2 score (18.9) than male patients (19.9). One explanation for these results may be that a moderately impaired patient would receive the same PSMS1 score as a severely impaired patient. Therefore, despite the slight difference in the mean, the PSMS2 scores indicated that the male patients as a whole were not quite as severely impaired as the female patients.

The modal patient in this sample was a caucasian male of 77.3 years who had been suffering from Alzheimer's disease an estimated 7.9 years. The modal patient was described by the caregiver to be in the sixth stage of

Table 6

Patient Characteristics

	Male Patients	Female Patients	All Patients
Patient Age			
M	75.7	79.3	77.3
SD	8.7	8.8	8.8
RANGE	64-93	61-94	61-94
Number of Years the Patient has had Alzheimer's Disease			
M	7.6	8.3	7.9
SD	2.7	5.0	3.8
RANGE	3-12	1-17	1-17

n=30

Table 7

Patient's Physical Self-Maintenance Scores

	Male Patients	Female Patients	All Patients
PSMS1			
M	1.8	1.9	1.9
SD	2.0	1.8	1.9
RANGE	(0-6)	(1-5)	(0-6)
PSMS2			
M	19.9	18.0	19.5
SD	7.0	7.9	7.3
RANGE	(7-30)	(7-29)	(7-30)

n=30

Alzheimer's disease. The patient had lived in the home an average of 15.2 years (range of 0.5 to 41 years).

Incidence of Problem Behaviors

These analyses examine the frequency of common memory and behavior problems that often accompany the process of Alzheimer's disease. Table 8 rank orders the sixteen problems that were adapted from the Memory and Behavior Problem Checklist (Zarit et al. 1985) and the Physical Self-Maintenance Scale (Lawton and Brody, 1969). The problems are ranked from difficulty in doing simple tasks, which was experienced by the most caregivers, to the patient engaging in behaviors dangerous to others, which was experienced by the least number of caregivers interviewed in this study. The five highest ranked problem behaviors were reported by 90% or more of the caregivers. Thus they appear to be encountered almost universally.

Because the course of Alzheimer's disease varies from patient to patient, and each patient's condition can vary from month-to-month or day-to-day, a caregiver often encounters different problems at different stages of the disease. Some problem behaviors may never occur, or may occur for only a short period or sporadically, while other problems may continue to occur throughout the duration of the disease. Thus one caregiver may be faced with almost all of the problems included in the study, while another

Table 8

Rank Order of the Incidence of Problem Behaviors

Problem	Rank	Percentage of Caregivers Reporting Problem Behavior
Difficulty Doing Simple Tasks	1	97% (n=29)
Losing Things	3	93% (n=28)
Forgetting What Day it is	3	93% (n=28)
Difficulty Grooming Self	3	93% (n=28)
Difficulty Bathing Self	5	90% (n=27)
Waking Caregiver Up at Night	6	87% (n=26)
Difficulty Dressing Self	7	77% (n=23)
Dangerous to Self	9	70% (n=21)
Seeing or Hearing Things	9	70% (n=21)
Difficulty Toileting Self	9	70% (n=21)
Wandering	11.5	67% (n=20)
Destroying Property	11.5	67% (n=20)
Hiding Things	13.5	60% (n=18)
Difficulty Feeding Self	13.5	60% (n=18)
Difficulty Moving Around	15	47% (n=14)
Dangerous to Others	16	43% (n=13)

n=30

caregiver may only be confronted by a few of those problems.

There are also many other memory and behavior problems not specifically addressed in this study which may arise during the course of the disease. A total of 32 other problems were reported by caregivers. Of those, 22% were environmental in nature. Listed below are the problems that were mentioned by the caregivers interviewed that involved the physical environment (see Appendix I for a complete list of the additional problems reported).

1. Patient having difficulty adjusting to move into relative's home
2. Patient constantly getting into things and making a mess (ex. patient taking food from freezer and hiding it in bedroom drawers, rearranging drawers or emptying closets, etc.)
3. Patient closing windows (during the summer)
4. Patient refusing to let caregiver out of sight (no privacy)
5. Patient having difficulty riding in car or getting in and out of car
6. Patient being at risk for falls and other safety concerns
7. Caregiver experiencing physical stress from lifting and turning bedridden patient

Amount of Caregiving Stress

The stress scores from all of the 16 memory and behavior problems which applied to each caregiver were complied into a composite score. The mean stress score for caregivers across all memory and behavior problems reported was 4.00 (SD=2.90), with scores ranging from 1 to 10. Thus caregivers experienced a wide range of perceived stress associated with caring for a person with Alzheimer's disease.

Table 9

Rank Order of Stress Ratings for Problem Behaviors

Problem Behavior	Rank	M	SD	RANGE
Dangerous to Self	1	4.95	3.50	1-10
Hiding Things	2.5	4.56	3.07	1-10
Difficulty Bathing Self	2.5	4.56	3.27	1-10
Difficulty Dressing Self	4	4.52	2.92	1-9
Waking Caregiver Up at Night	5	4.46	3.18	1-10
Wandering	6	4.40	3.03	1-10
Losing Things	7	4.36	2.66	1-10
Dangerous to Others	8	4.31	2.84	1-10
Difficulty Doing Simple Tasks	9	4.21	3.05	1-10
Difficulty Toileting Self	10	4.00	3.02	1-10
Destroying Property	11	3.75	2.55	1-8
Difficulty Feeding Self	12	3.50	2.09	1-8
Seeing or Hearing Things	13	3.33	2.31	1-8
Difficulty Grooming Self	14	3.25	2.89	1-10
Difficulty Moving Around	15	3.00	2.42	1-8
Forgetting What Day it is	16	2.82	2.98	1-10

n=30

Table 9 displays the rank order for the amount of stress experienced by all caregivers as a result of the occurrence of each of the 16 memory and behavior problems. The mean stress rating for memory and behavior problems was 4.00 (SD=0.64), with scores ranging from 4.95 for the patient engaging in behavior dangerous to self to 2.82 for forgetting the day. According to the caregivers, the most stressful memory and behavior problems are those behaviors that could endanger the safety and well-being of the Alzheimer's disease patient. For example, the patient engaging in behaviors dangerous to self was the problem behavior category with the highest mean stress rating.

Other memory & behavior problems such as the patient having difficulty bathing or waking the caregiver up at night may have been very stressful because they took a physical and/or mental toll on the caregiver. Not receiving adequate sleep may make dealing with the problems of caregiving even more difficult. A caregiver who is tired may not adequately evaluate all of the possible ways of handling problems, so many effective solutions, including some types of environmental interventions, may be overlooked.

The next group of memory and behavior problems probably were perceived as stressful because they occurred frequently and required much of the caregiver's time and attention. The problems of the patient having difficulty doing simple

tasks and the patient losing or misplacing things were two of the frequent memory and behavior problems reported (see Table 8). The problems of the person having difficulty grooming, and forgetting what day it was were given some of the lowest stress ratings. Although these problems occurred frequently, (with 93% of the patients interviewed), they may have seemed less stressful because they often required less caregiver time and were not life threatening.

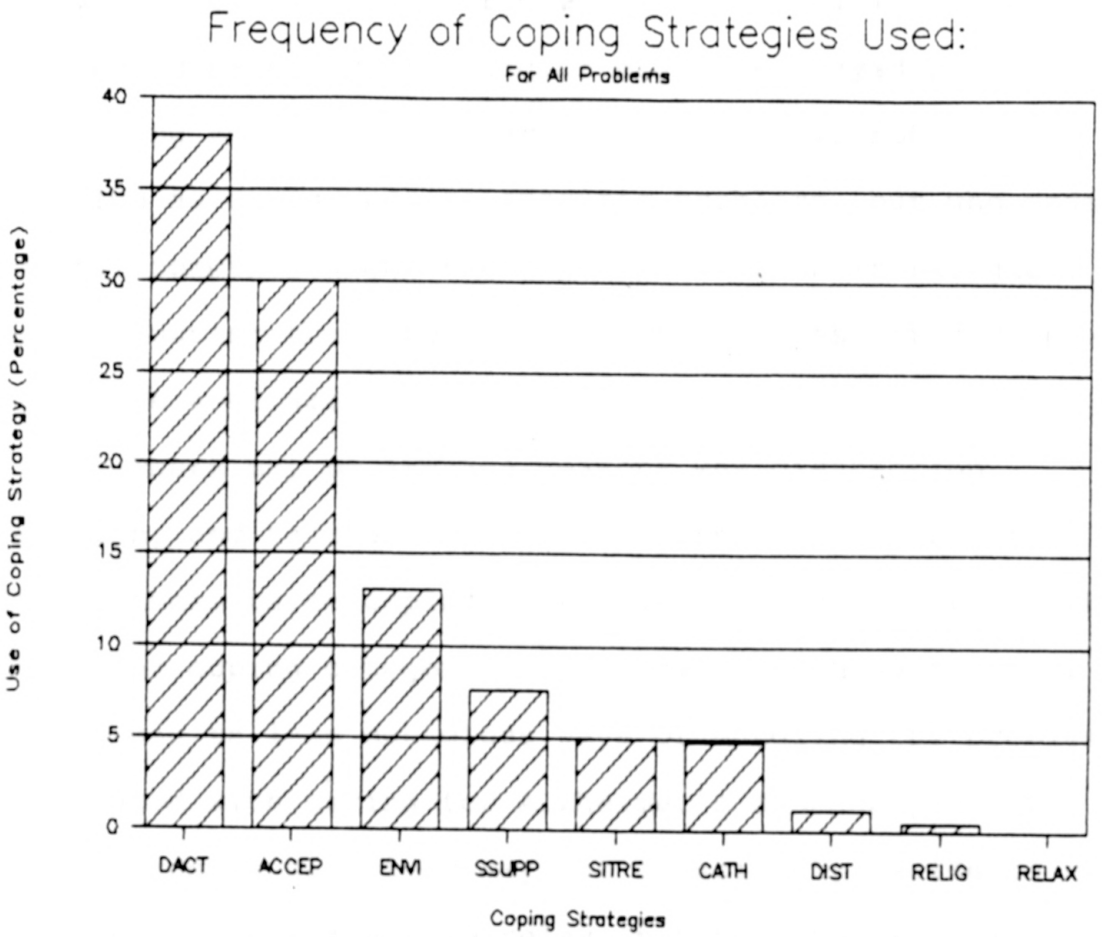
Coping Strategies

During the interviews, caregivers were asked to describe from a list of coping categories how they handled each of the memory and behavior problems when they occurred. The list included the following coping categories and their definitions: distraction, situation redefinition, environmental intervention, direct action, catharsis, acceptance, seeking social support, relaxation, and religion. A tenth category "other" also was offered, but was never used.

Figure 4 shows that the most frequently used coping categories by the caregivers were direct action (38%) and acceptance (30%), followed by environmental intervention (13%). These first two coping categories seemed to be predominant elements in a caregivers' approaches to the problems of caring for an Alzheimer's disease patient.

The three coping categories of distraction, religion,

Figure 4



DACT = Direct Action

ACCEP= Acceptance

ENVI = Environmental Intervention

SSUPP= Social Support

SITRE= Situation Redefinition

CATH = Catharsis

DIST = Distraction

RELIG= Religion

RELAX= Relaxation

and relaxation combined made up less than 2% of the coping strategies used. However, these coping categories may have actually been used more frequently than they were reported. The coping category of religion may have played an underlying role for some caregivers, who did not list religion as a response to specific problems, but who made general comments about the importance of their religious beliefs during the interview and whose homes often displayed religious artifacts.

There may be several reasons why distraction, religion, and relaxation were not reported very often. First, these three coping categories are more abstract than the other coping categories. Engaging in these types of coping may be less conscious ways of handling the problems associated with caring for Alzheimer's disease patients. In other words, a caregiver may not consciously decide to sit down and watch a movie to relax in hopes that it will help in coping with a problem that just occurred. Second, the coping categories distraction, religion, and relaxation, may not be thought of as ways to cope with one specific memory or behavior problem, but as ways of coping with a series of difficult events or the overall stress of caregiving. For example, a caregiver might respond to each of a series of problems in the day, such as wandering, grooming, and losing things with specific direct actions, but find that the accumulation of problems leads to seeking relaxation or

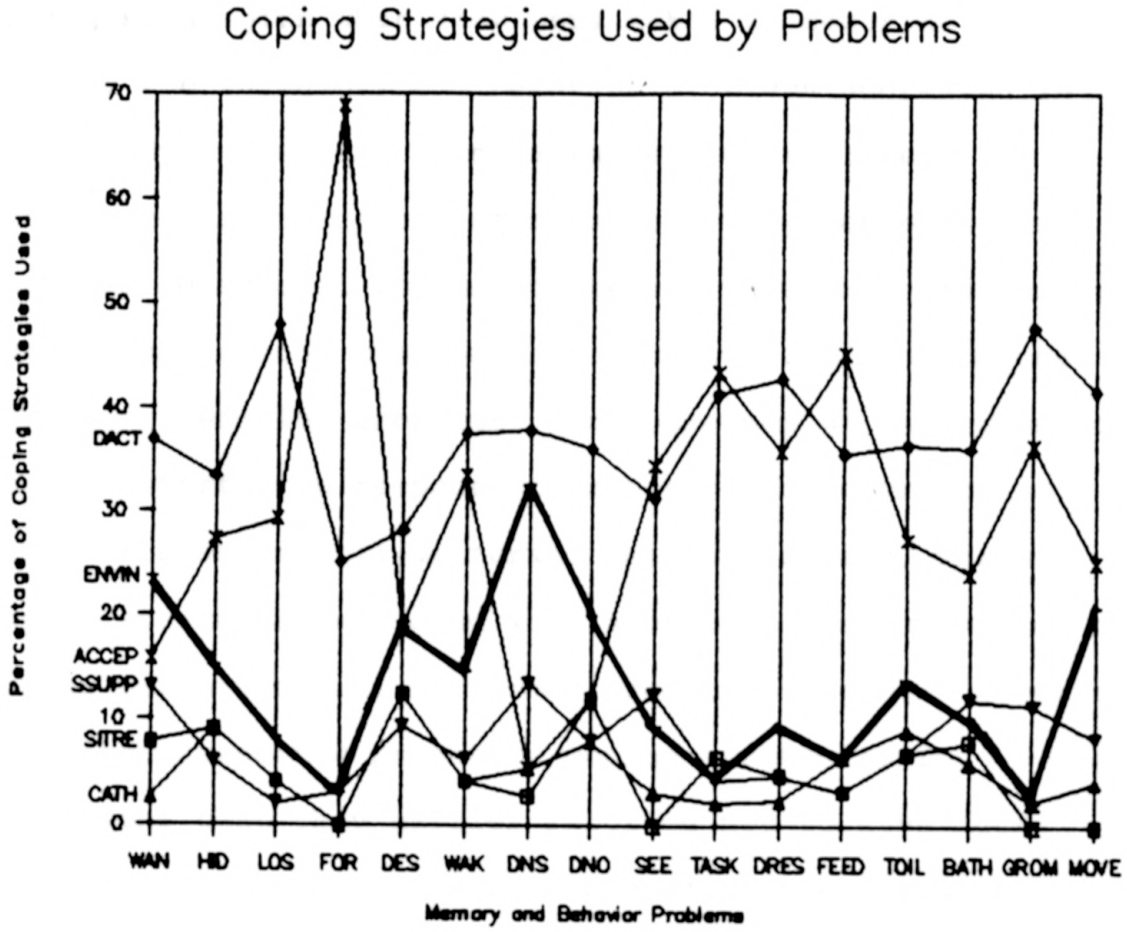
distraction.

Environmental Coping

As mentioned earlier the category "environmental intervention" was added to Stone and Neale's (1984) list of eight coping categories in order to assess the role that the physical environment plays when caregivers try to handle or solve these common memory and behavior problems. Across all caregivers and all memory and behavior problems, 7% of the caregivers reported that they never used environmental intervention at all. The remaining caregivers tried environmental interventions a total of 341 times. Of those interventions tried, 298, or 87% were reported by the caregivers to be successful.

Figure 5 illustrates the use of environmental coping by the type of problem, displayed within the context of other frequently used strategies. The coping strategies of distraction, religion and relaxation were omitted from this illustration because combined they were employed less than 2% of the time. The variation of strategy by problem is apparent. Never did environmental strategies take precedence over other forms of direct action, and only occasionally over forms of acceptance. However, the use of environmental intervention as a way of handling the each problem was consistently favored over the coping strategies of social support, situation redefinition, and catharsis.

Figure 5



Memory and Behavior Problems

WAN = Wandering
HID = Hiding Things
LOS = Losing or Misplacing Things
FOR = Forgetting the Date
DES = Destroying Property
WAK = Waking Caregiver Up at Night
DNS = Behaviors Dangerous to Self
DNO = Behaviors Dangerous to Others
SEE = Seeing or Hearing Things
TASK= Difficulty Doing Simple Tasks
DRES= Difficulty Dressing Self
FEED= Difficulty Feeding Self
TOIL= Difficulty Toileting Self
BATH= Difficulty Bathing Self
GROM= Difficulty Grooming Self
MOVE= Difficulty Moving Around

Coping Strategies

DACT = Direct Action

ENVIN= Environmental Intervention

ACCEP= Acceptance

SITRE= Situation Redefinition

CATH = Catharsis

Proactive versus Reactive Coping

As discussed above, caregivers reported a range of coping strategies when they were asked to describe how they handled the 16 memory and behavior problems addressed in this study. However, when caregivers were closely questioned about the coping behaviors they employed they reported additional coping strategies that they had used to address situations they had not perceived or reported as memory or behavior problems. For purposes of this research, coping reported in response to a perceived memory or behavior problem will be termed reactive coping, while coping strategies employed when a problem was not yet or no longer perceived will be termed proactive coping. Since the caregivers reported proactive coping strategies for situations that they earlier reported not to have been problems, it was not possible to examine the specific relationships between stress, control, and coping in these cases because data were not collected on those variables.

Over half (53%) of the caregivers reported proactive coping strategies, accounting for 6% of the total coping strategies reported. Proactive coping strategies were most commonly employed for the memory and behavior problems that could endanger the safety or well-being of the patient or those people around the patient. The three problems for which the caregivers reported the most proactive coping strategies were: (1) the patient engaging in behaviors

dangerous to self (29%), (2) wandering (18%), (3) and the patient engaging in behaviors dangerous to others (18%). These situations may not have been perceived as problems because the caregivers' actions were proactive and may have prevented the problem from occurring.

Direct action (44%) was the most common proactive coping strategy employed by caregivers. Environmental intervention (24%) and acceptance (24%) also were frequently employed, following the pattern of distribution identified for reactive coping. Social support and distraction made up the remaining 7% of the proactive coping strategies reported.

It is important to note that memory and behavior problems may change or worsen as the disease progresses, and that the coping strategies related to these problems also frequently change. A solution that worked for a problem last week, may not work this week. Thus, the next set of analyses examined differences in problems, stress and coping by the stage of Alzheimer's disease which the patient was experiencing.

CHAPTER FOUR

ANALYSES OF FREQUENCY, STRESS, CONTROL, AND ENVIRONMENTAL COPING BY PROBLEM AND BY STAGE OF DISEASE

The analyses in this chapter explore the stress, control, and coping associated with each of the 16 memory and behavior problems. Differences by stage in frequency, stress, control, and types of coping including environmental interventions are discussed. Since only two caregivers cared for patients in stage six, the statistical analyses of frequency, stress, and control by stage were limited to caregivers of patients in stages five, six, and seven. The statistical analyses involving all of the coping strategies and those which specifically address environmental intervention include the caregivers in stage six.

Wandering

Wandering is a memory and behavior problem that occurs frequently and is often very irritating and stressful for the caregivers. A total of 67% of the caregivers interviewed (including stage four) were at some time confronted by the problem of wandering. The mean stress rating for wandering was 4.40, (SD=3.03), and was above the median stress rating of 4.26 experienced by all caregivers for all of the memory and behavior problems.

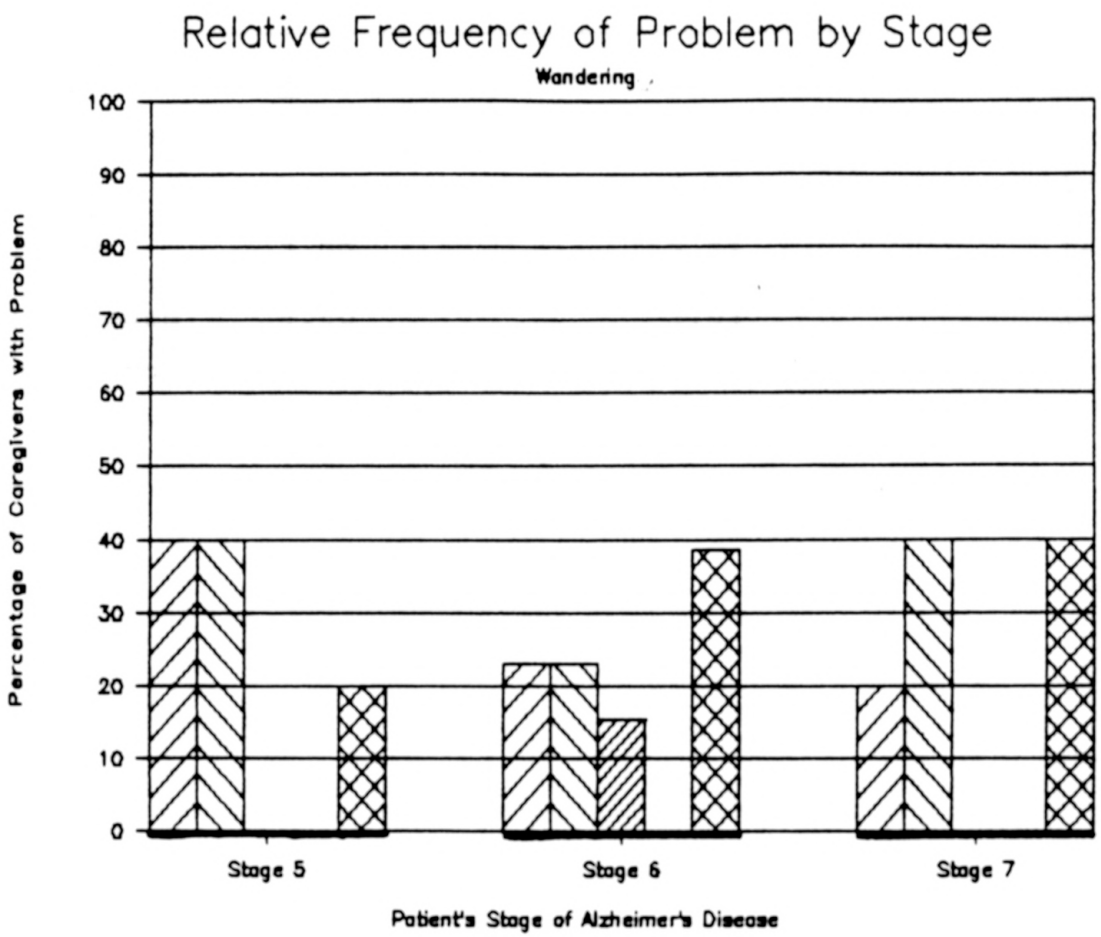
Frequency of Wandering

Wandering appeared to be a problem with which caregivers were confronted throughout the later course of the disease until the patient became bedridden. According to the results presented in Figure 6, in the earlier stages of Alzheimer's disease wandering occurred less frequently. Of the patients in stage five, 40% of the caregivers had never been confronted by the problem of wandering, while another 40% of the caregivers reported that wandering had occurred, but not in the past week. The remaining 20% were confronted by the problem daily or more often. Wandering in the earlier stages of the disease may result from the patient becoming lost, confused, or disorientated and simply forgetting the way home or what he or she was supposed to be doing. In the later stages of Alzheimer's disease it appears that wandering may occur more frequently. Instead of the patients wandering occasionally, most caregivers reported that they wandered once or twice a week to daily or more often.

Stress Associated with Wandering

The correlation between the frequency of wandering and the stress associated with this problem by the caregivers was not statistically significant ($r=0.16$, $p=.20$). The mean stress scores associated with wandering by stage of the disease are shown in Table 10. They ranged from 1 to 10 and

Figure 6



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Table 10

Amount of Stress Perceived by Caregivers Wandering

Stage	M	SD	Range
5	3.50	1.52	1-5
6	5.30	3.56	1-10
7	3.50	3.32	1-8
All Stages	4.40	3.03	1-10

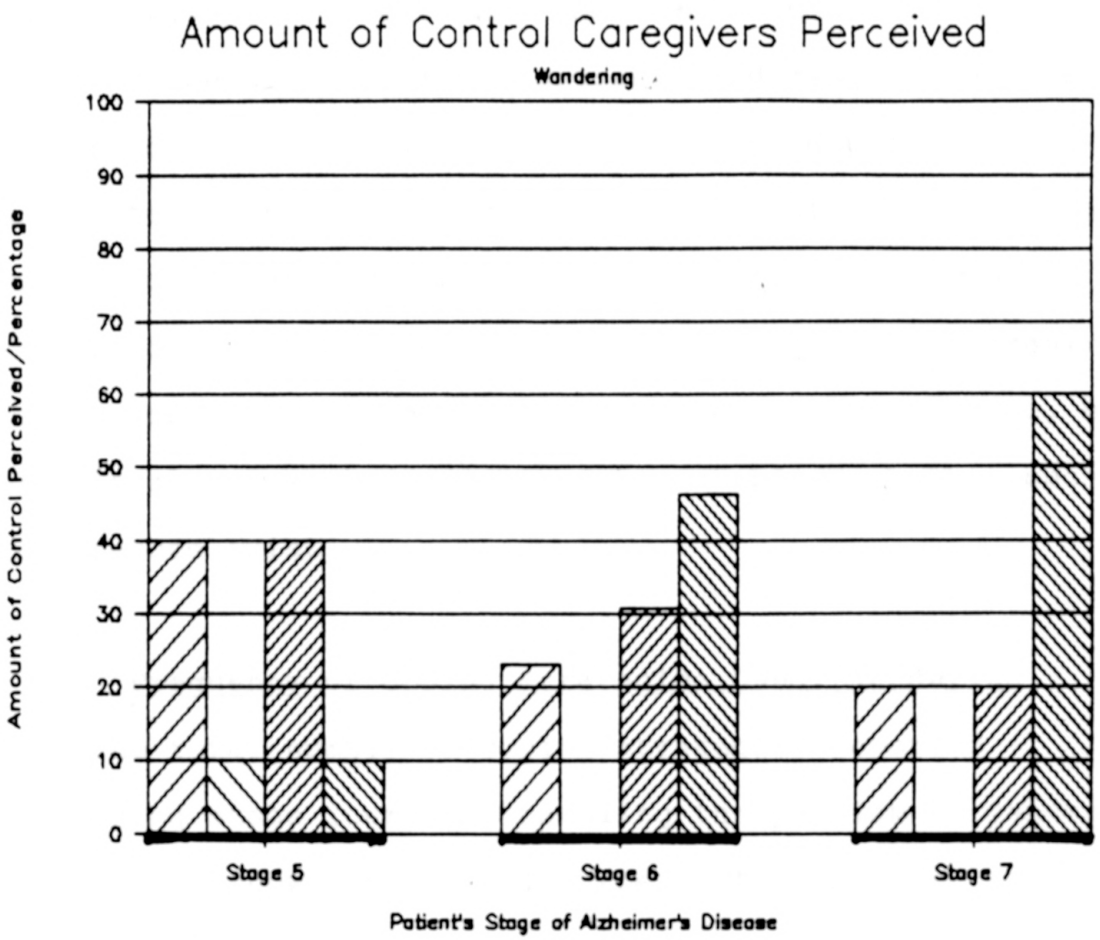
n=20

about constant or agitated wandering or a patient's determined effort to get away. The highest mean stress score by stage was experienced by the caregivers caring for patients in the sixth stage of Alzheimer's Disease (see Table 10). One explanation for the high stress experienced by these caregivers may be that many patients in the sixth stage are still ambulatory, but their mental reasoning, judgement and orientation have become severely impaired. Thus, they may become greater risks to themselves. A Kruskal-Wallis test, a nonparametric alternative to the one-way analysis of variance, was conducted to examine the differences in stress reported by caregivers of patients in stages five, six, and seven. The results of this analysis were not statistically significant ($H^{1}=2.25$, $k=3$, $\underline{n}=20$) supporting the suggestion that wandering is a consistently stressful problem for caregivers throughout the later stages of Alzheimer's disease.

Caregiver Control: Wandering

For the problem of wandering, the study identified no significant linear relationship between stress and control ($r=-0.29$, $\underline{p}=.06$). As shown in Figure 7, in the sixth stage of Alzheimer's disease, 50% of the caregivers felt that they either had extensive or at least some control over the problem of wandering. However, in later stages of the disease, caregivers reported less control over handling this

Figure 7


Amount of Control Caregivers Perceived
Wandering
Amount of Control Perceived/Percentage
100
90
80
70
60
50
40
30
20
10
0
Stage 5
Stage 6
Stage 7
Patient's Stage of Alzheimer's Disease
= Problem doesn't apply
= Quite a lot/complete control
= Some control
= No control

problem. Of the caregivers caring for patients in stage high scores were often associated with caregiver commentsseven, 60% felt that they had no control over handling the problem of the patient wandering. When the differences in control by stage were tested using a Kruskal-Wallis test, the differences approached but did not reach statistical significance (H^{1}=5.64, k=3, $\underline{n}$=20). There may be differences in the amount of control perceived by caregivers caring for patients in different stages of the disease, but additional research is required to establish whether such differences exist.

Frequency of Coping Strategies Used: Wandering

The total number of coping strategies reported (including stage four) for handling the problem of wandering was 38. As shown in Table 11, the most common way of handling this problem was direct action. Most caregivers reported that they would retrieve the patient and bring him or her back to the appropriate location. Some caregivers found it helpful to have the patient wear an identification bracelet with "Memory Impaired" and the caregiver's phone number engraved on it. They also notified neighbors and the local police department of the patient's condition and the potential problem of wandering before the problem occurred. Other coping strategies such as environmental intervention, acceptance and social support were used less frequently to

Table 11

Rank Order of Coping Strategies Used Wandering

Coping Strategy	Percentage Used
Direct Action	37% (n=14)
Environmental Intervention	24% (n=9)
Acceptance	16% (n=6)
Social Support	13% (n=5)
Situation Redefinition	8% (n=3)
Catharsis	3% (n=1)
Distraction	0% (n=0)
Relaxation	0% (n=0)
Religion	0% (n=0)

n=20

cope with the problem of wandering (see Table 11).

Frequency of Environmental Intervention: Wandering

Environmental intervention was the second most frequent way of handling this problem. A Kruskal-Wallis test was employed to examine any differences in environmental management (i.e., the proportion of environmental strategies used in relation to all other coping strategies) employed by the caregivers caring for patients in the three different stages of the disease. The results of the analysis were not statistically significant (H^{1}=45.99, k=3, $\underline{n}$=20), and the high frequency of tied scores suggests little variation between stages.

When caregivers were questioned in detail about environmental interventions, they reported a number of different interventions they had tried throughout the course of the disease to prevent wandering. A total of 27 environmental interventions were employed by caregivers; of those approximately 96% were reported to have been successful. The most common environmental intervention used by caregivers was locking the doors. Changing the lock sometimes also helped because a person with Alzheimer's disease had difficulty learning how to operate a new lock. Other caregivers added an inexpensive hook or lock at the top or bottom of the door to provide added security. One of the caregivers interviewed had all of the exterior door

locks reversed so that the person had to use a key to get out. (This solution can not be recommended because it could have very dangerous consequences. Occupants in the case of fire may find it impossible to exit, and also intruders have easy access into the home.)

Shutting or locking doors were used to keep the person with Alzheimer's disease either in or out of a room. These types of environmental interventions fall into Pynoos and his associate's (1988) environmental management strategy of restricting or changing areas. One caregiver had the rest of the family members lock their bedroom doors at night so that they could sleep when the person with Alzheimer's disease got up and wandered. In some instances caregivers intentionally chose not to lock the doors because the locked doors made the patient very upset and sometimes violent. When locks were not feasible, many caregivers placed bells on the doors or used other types of alarm systems to notify them when the patient was trying to leave a room or the house. Child gates and physical barriers in front of stairs and doors were also helpful to a number of caregivers.

Hiding Things

People suffering from Alzheimer's disease often put something down and forget where they put it. It is also common for them to become overly suspicious and hide or hoard items somewhere they feel they will be secure, and

then forget where they have hidden them. A total of 60% of the caregivers interviewed said that they were at some time confronted by the problem of the person hiding things. The mean stress score was 4.56, (SD=3.07) with scores ranging from 1 to 10.

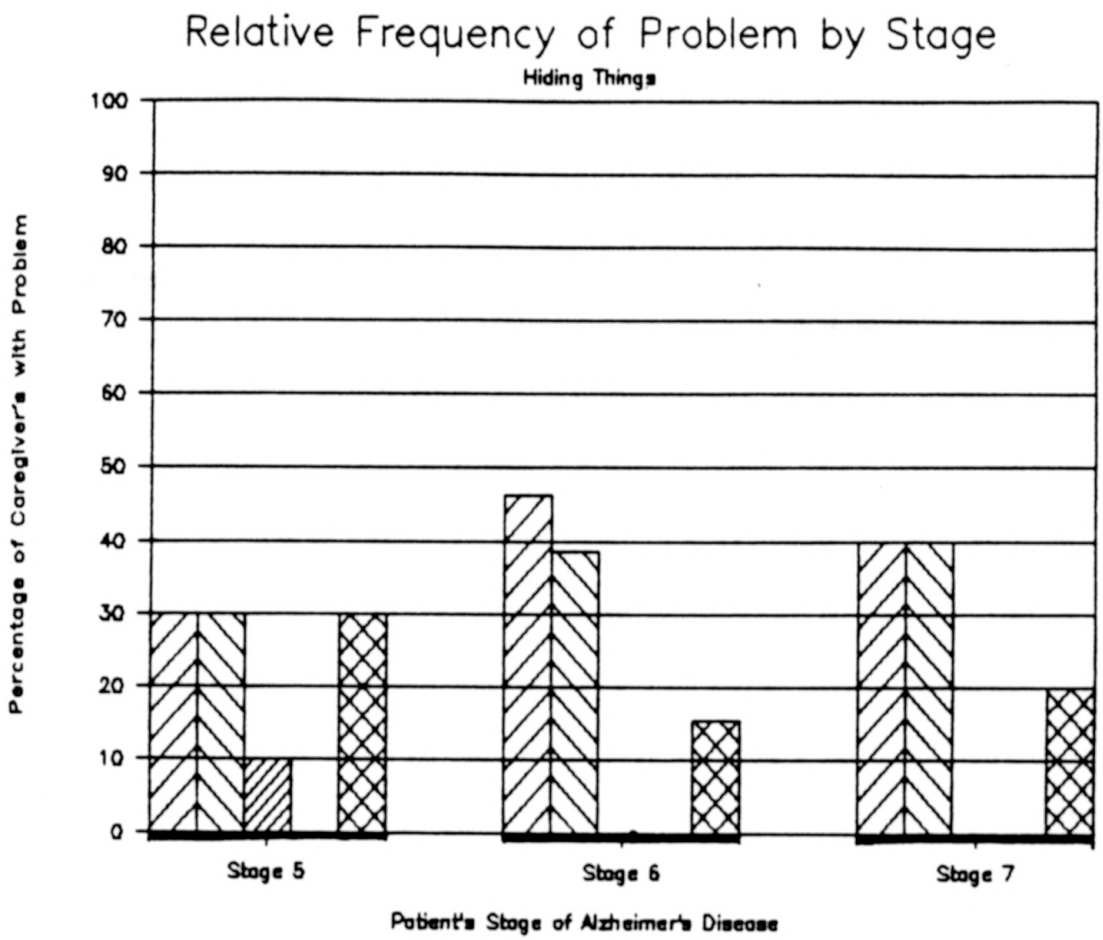
Frequency of Hiding Things

As illustrated in Figure 8, the problem of hiding things occurred occasionally throughout the last three stages of Alzheimer's disease. Most of the caregivers reported that the problem had occurred, but not in the past week. The caregivers caring for patients in the fifth stage of the disease reported the highest frequency of the problem. Here, 30% of the caregivers reported that this problem had occurred daily or more often. In stages six and seven, most of the caregivers reported that this problem had not occurred in the past week.

Stress Associated with Hiding Things

There was not a significant linear relationship between the frequency of the problem of hiding things and the stress associated with the problem of hiding things by the caregivers ($r=0.24$, $p=.11$). However, this problem was one of the most stressful of all of the memory and behavior problems experienced by caregivers. As shown in Table 12, the highest mean of stress reported by stage was 6.29, and

Figure 8



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Table 12

Amount of Stress Perceived by Caregivers Hiding Things

Stage	M	SD	Range
5	6.29	3.20	2-10
6	3.57	2.30	1-7
7	3.33	4.04	1-8
All Stages	5.56	3.07	1-10

n=18

was experienced by the caregivers caring for patients in the fifth stage of Alzheimer's disease. The mean stress scores declined in stages six and seven. A Kruskal-Wallis test was conducted to examine the differences in stress between stages five, six, and seven. The results of this analyses did not reach statistical significance (H^1=-1.53, k=3, $\underline{n}$=17).

Although for most caregivers the problem of the person hiding things only occurred occasionally, the high stress reported may be attributed to several reasons. Some caregivers became very upset when the items that had been hidden were very important, valuable or nonreplaceable. Other caregivers became very annoyed when they couldn't find items when they were in a hurry or really needed them. For example, a caregiver reported being late for an important meeting, and finding that the car keys had vanished.

Caregiver Control: Hiding Things

The correlation between stress and control (r=-0.10, $\underline{p}$=.29) for the problem of hiding things was not statistically significant. When the control ratings for all the stages of Alzheimer's disease were combined, there were the same number of caregivers reporting each category of perceived caregiver control: 20% perceived they had extensive control over this problem, 20% perceived they had some control, and 20% perceived they had no control over

this problem. The remaining 40% did not experience the problem.

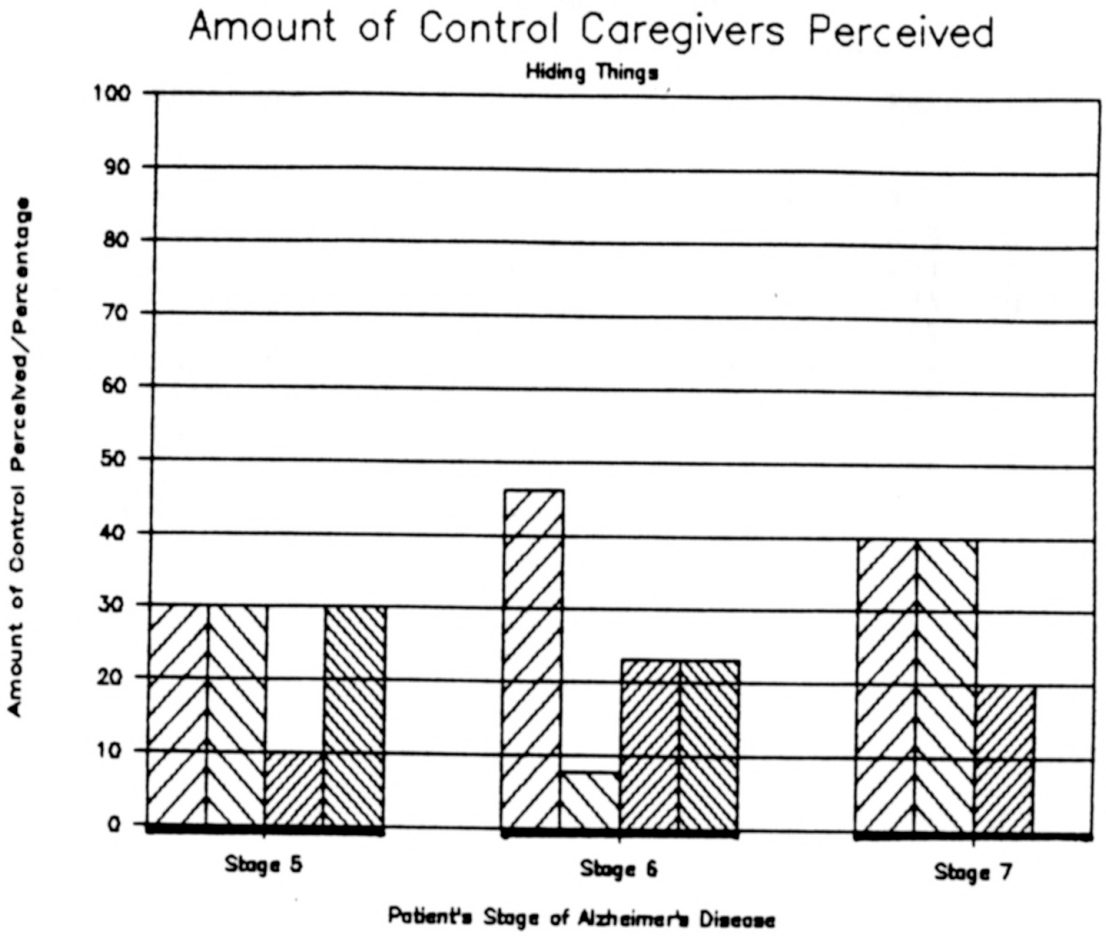
The distribution of control as shown in Figure 9 does not suggest a pattern by stage in the amount of control caregivers perceived for the problem person hiding things. Perceptions of extensive control or some control over this problem fluctuated across stages. The perceptions of no control over this problem declined slightly between caregivers of patients in stages five and six, and in the seventh stage this response was not reported. When these differences in control by stage were examined using a Kruskal-Wallis test, the differences were not statistically significant (H^1=2.19, k=3, $\underline{n}$=17).

Frequency of Coping Strategies Used: Hiding Things

The total number of coping strategies reported for handling the memory and behavior problem of hiding things was 33. According to Table 13, the most common way of handling the problem was direct action. Most caregivers reported that when they couldn't find something, they would simply go look for the hidden item. They also would try to keep track of frequently hidden items. Caregivers reported that it was easier to find items once they learned the patients' favorite hiding places.

Acceptance was the second most frequently use coping strategy for dealing with the problem of the person with

Figure 9



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

Table 13

Rank Order of Coping Strategies Used Hiding Things

Coping Strategy	Percentage Used
Direct Action	33% (n=11)
Acceptance	27% (n=9)
Environmental Intervention	15% (n=5)
Situation Redefinition	9% (n=3)
Catharsis	9% (n=3)
Social Support	6% (n=2)
Distraction	0% (n=0)
Relaxation	0% (n=0)
Religion	0% (n=0)

n=18

Alzheimer's disease hiding things. Approximately 27% of the caregivers reported that accepting the fact that this problem was likely to happen helped them to prepare for this behavior before it happened, and helped them handle the problem better when it did happen.

Frequency of Environmental Intervention: Hiding Things

Environmental intervention was the third most frequently used strategy. A Kruskal-Wallis test was employed to examine the differences in environmental management by the different stages of the disease. The results of this analysis were not statistically significant (H^1=-59.47, k=3, $\underline{n}$=17), and there were too many tied scores.

A total of 16 environmental interventions were employed by the caregivers. Of the many different environmental interventions employed, 100% were reported to have been successful. First, most of the caregivers tried to reduce the number of items that could be hidden. One way of doing this was to reduce the amount of clutter in the house. Second, many caregivers gradually put away or stored important, valuable, or sentimental items they did not want lost or broken. They also did not leave things in view around the house that the patient might hide. These environmental interventions fit into Pynoos and his associates (1988) environmental management strategy of removing or modifying objects. According to Noelker (1982),

insufficient storage space was reported by 20% of the caregivers in her study and often went uncorrected. These findings suggest that the caregivers may have an unrecognized need for increased storage.

Most caregivers also tried to reduce the number of places items could be hidden. The following environmental interventions reported by the caregivers fell into Pynoos and his associates' (1988) environmental management strategy of restricting or changing areas. One strategy was locking doors and cabinets in order to keep the patient from hiding objects inside these areas. Locking doors and cabinets and the use of child gates often were effective in keeping the Alzheimer's disease patient from taking objects out of these areas and hiding items somewhere else. Emptying shelves and drawers or reducing the number of items kept in these places not only reduced the number of items that could be hidden, but it also made it easier for the caregiver find hidden or lost items. Some caregivers more than others seemed to be aware of which objects the patient might hide and where the patient's favorite hiding places were located. Thus, these caregivers may be more successful in targeting the objects to be removed, the places that should be controlled, the places clutter should be reduced, and the places to start looking when something is missing.

Although most caregivers did not like having to change their own environments, they preferred removing valuable or

sentimental objects from areas accessible to the patient instead of taking the risk having those objects lost forever. The decision to store an object depended on the attachment and value that object had to the caregiver and other family members. Caregivers stored these objects in attics, basements, garages, spare bedrooms, and closets or chests. However, a few caregivers felt that these objects belonged to the patient, and that the patient had the right to do what ever he or she wanted to do with such personal belongings. According to Pynoos and his associates (1988) many caregivers are reluctant to change or modify their environments because of the temporary nature of many of the Alzheimer's disease patient's problem behaviors.

Losing or Misplacing Things

Although people suffering from Alzheimer's disease often hide or hoard items, it is also very common for the patients to simply set something down and forget where it was put. In any case, these items often become lost or misplaced. A total of 93% of the caregivers interviewed said that at some time they were confronted by the memory and behavior problem of the person losing or misplacing things. Losing or misplacing things was the seventh most stressful memory and behavior problem, with a mean score of 4.36 (SD=2.66), and scores ranging from 1 to 10.

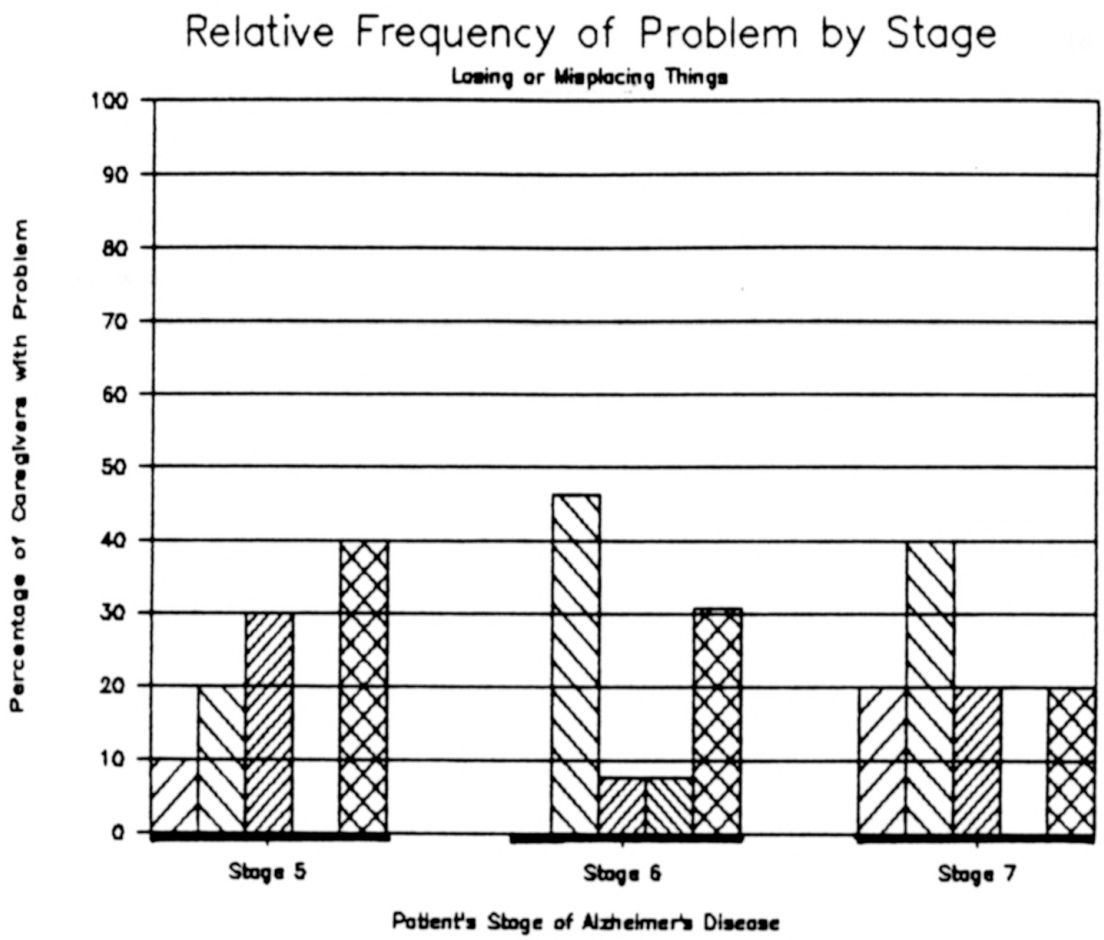
Frequency of Losing or Misplacing Things

The problem of losing or misplacing things was one of most frequent memory and behavior problems experienced by caregivers (see Table 8). According to Figure 10, this problem seemed to occur most frequently in stage five. Here 30% of the caregivers reported that this problem occurred once or twice in the past week, while another 40% reported that this problem occurred daily or more often. The percentage of caregivers who reported that the problem occurred daily or more often declined to approximately 31% in stage six and to 20% in stage seven. One reason for the decline in the frequency of this problem in the later stages may be the patient's decreasing mobility.

Stress Associated with Losing or Misplacing Things

The Pearson Product Moment correlation coefficient between frequency of losing or misplacing things and the stress associated with the problem by the caregiver ($r=0.43$, $p=.009$) indicated a significant linear relationship between the two variables. This finding suggests that greater frequency of losing or misplacing things was associated with greater perceived stress. The greatest mean stress score by stage reported was 6.33 (shown in Table 14), and was experienced by caregivers caring for patients in the sixth stage of Alzheimer's disease. Caregivers for patients in stage seven experienced not only the highest level of

Figure 10



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Table 14

Amount of Stress Perceived by Caregivers Losing or Misplacing Things

Stage	M	SD	Range
5	6.33	2.29	3-10
6	3.31	2.25	1-7
7	3.75	3.40	1-8
All Stages	4.39	2.66	1-10

n=28

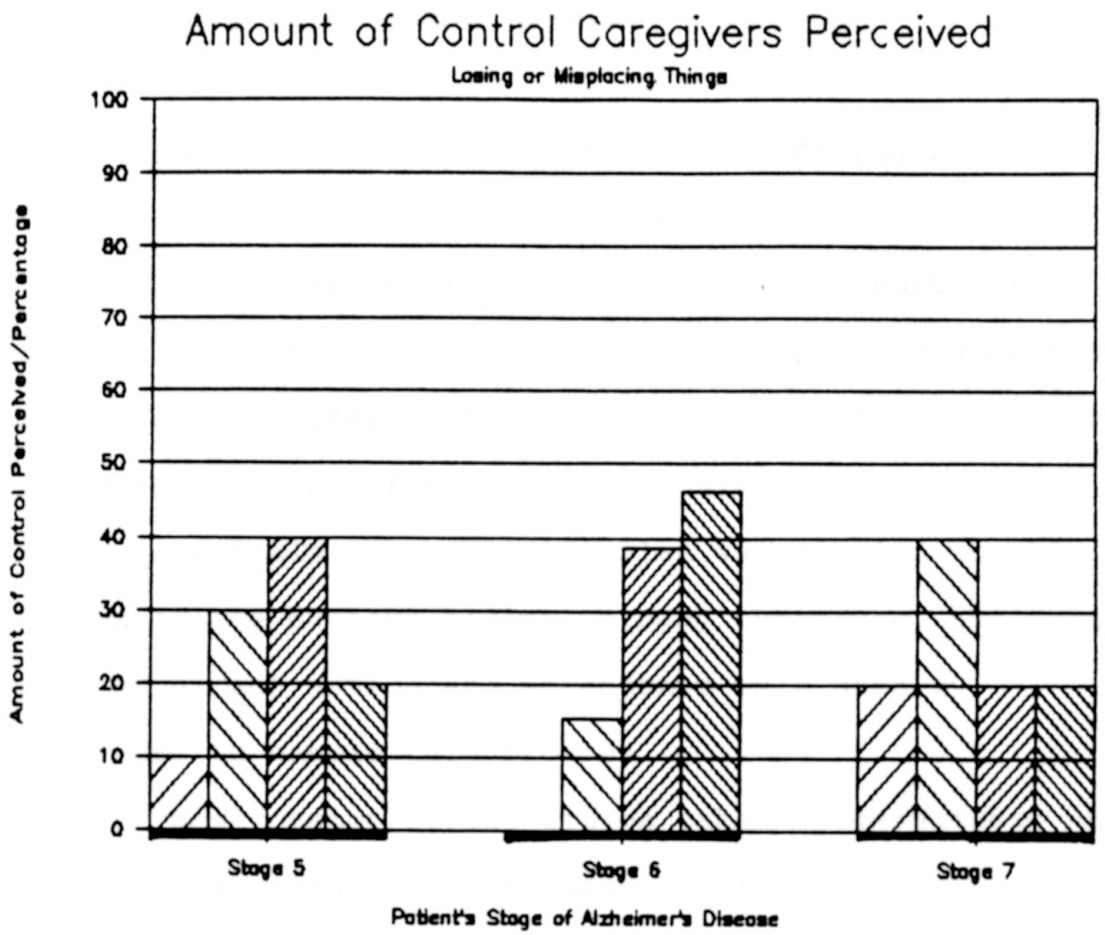
stress, but also high frequencies of occurrence for this problem.

A Kruskal-Wallis test was conducted to examine the differences in stress between caregivers of the patients in stages five, six, and seven. The results of this analysis approached but did not reach statistical significance (H^1=5.69, k=3, $\underline{n}$=26).

Caregiver Control: Losing or Misplacing Things

The correlation between stress and control for the problem of losing or misplacing things (r=-0.32, $\underline{p}$=.04) indicated a significant negative relationship between the two variables: greater perceptions of stress were associated with less perceived control. Figure 11 suggests that the amount of control caregivers perceived over handling the problem of losing things fluctuated between the stages of Alzheimer's disease. In the fifth stage of the disease, 30% of the caregivers perceived they had extensive control over handling this problem. In stage six, this percentage dropped to about 15%, but rose again to 40% in stage seven. The percentage of caregivers who perceived they had no control over handling the problem of the person losing or misplacing things fluctuated in the opposite direction. In stage five, 20% of the caregivers perceived that they had no control over handling this problem. This percentage rose to 46% in stage six, then dropped back down to 20% in stage

Figure 11



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

seven. When the difference in control by stage were examined using a Kruskal-Wallis test, the differences were statistically significant (H^1=6.81, k=3, $\underline{n}$=26).

Frequency of Coping Strategies Used: Losing or Misplacing Things

The total number of coping strategies reported for handling this problem was 48. Direct action and acceptance made up approximately 77% of the coping strategies used to handle the problem of the patient losing or misplacing things (see Table 15). This problem was similar to the problem of the patient hiding things; therefore, the same types of direct action and acceptance were used by caregivers to handle this problem.

The most common direct action taken by caregivers when something was missing was to look for the lost item. If the object could not be found and the patient needed that item, the caregiver usually replaced it. The patient's dentures were reported to be an item that the patient needed, but frequently lost. Patients also misplaced their glasses frequently. In this case, many caregivers found it somewhat helpful to try to put the glasses in the same place all the time when the glasses were not being worn. One patient didn't wear his reading glasses all of the time, and as a result, he kept losing his glasses. The caregiver solved the problem by buying him a pair of bifocals so that he

Table 15

Rank Order of Coping Strategies Used Losing or Misplacing Things

Coping Strategy	Percentage Used	
Direct Action	48%	(n=23)
Acceptance	29%	(n=14)
Environmental Intervention	8%	(n=4)
Distraction	4%	(n=2)
Situation Redefinition	4%	(n=2)
Catharsis	4%	(n=2)
Social Support	2%	(n=1)
Relaxation	0%	(n=0)
Religion	0%	(n=0)

n=28

could wear the glasses all the time.

When items that the patient really didn't need anymore were lost, most caregivers just didn't replace that item. For example, if a watch or inexpensive piece of jewelry was lost and the caregiver didn't replace that item, most patients simply forgot about the item or lost interest in it. However, many times patients insisted upon carrying certain things with them (e.g., keys, purse or billfold), and often become very upset when they could not find these items. In order to help keep track of the patient's keys, some caregivers found that buying a key chain that hooked to the patient's pants helped. Since it is more difficult to keep track of the patient's purse or billfold, caregivers tried to limit their contents to things of little value or importance to the patient. Some patients insisted upon having money in their billfold or purse even if they couldn't remember how to count the money. In this case, caregivers would limit the amount of money they gave the patient. Others found that giving the patient play money also worked.

Frequency of Environmental Intervention: Losing or Misplacing Things

Despite the relatively low number of caregivers who used environmental intervention, it was the third most frequent coping strategy used to handle this problem. A

Kruskal-Wallis test was completed to examine the differences in environmental management used by the caregivers caring for patients in the three different stages of the disease. The results were not statistically significant (H^1=-59.47, k=3, $\underline{n}$=17).

Direct questioning revealed that many of the same environmental interventions used to handle the problem of hiding things also were used to handle this problem, but the percentage of environmental intervention in relation to other coping strategies was used less frequently. A total of 17 environmental interventions were employed by caregivers, with 82% reported to have been successful. Caregivers reported that they tried to reduced the number of items in sight, and put away important, valuable, or sentimental items to prevent them from being lost. These types of environmental interventions are described by Pynoos and his associates (1988) as the environmental management strategy of removing or modifying objects. While patients were still able to read and understand what they had read, some caregivers found it helpful to leave the patient notes. For example, "This is your billfold. I have your money. Don't worry."

Forgetting What Day It Is

A person in the early stages of Alzheimer's disease often is able to remember events that happened a long time

ago, but has much difficulty remembering current events. Approximately 93% of the caregivers interviewed said that they were at sometime confronted by the problem of the person with Alzheimer's disease forgetting what day it was. This problem was the least stressful memory and behavior problem experienced by caregivers with a mean score of 2.82 (SD= 2.98), but with scores still ranging from 1 to 10.

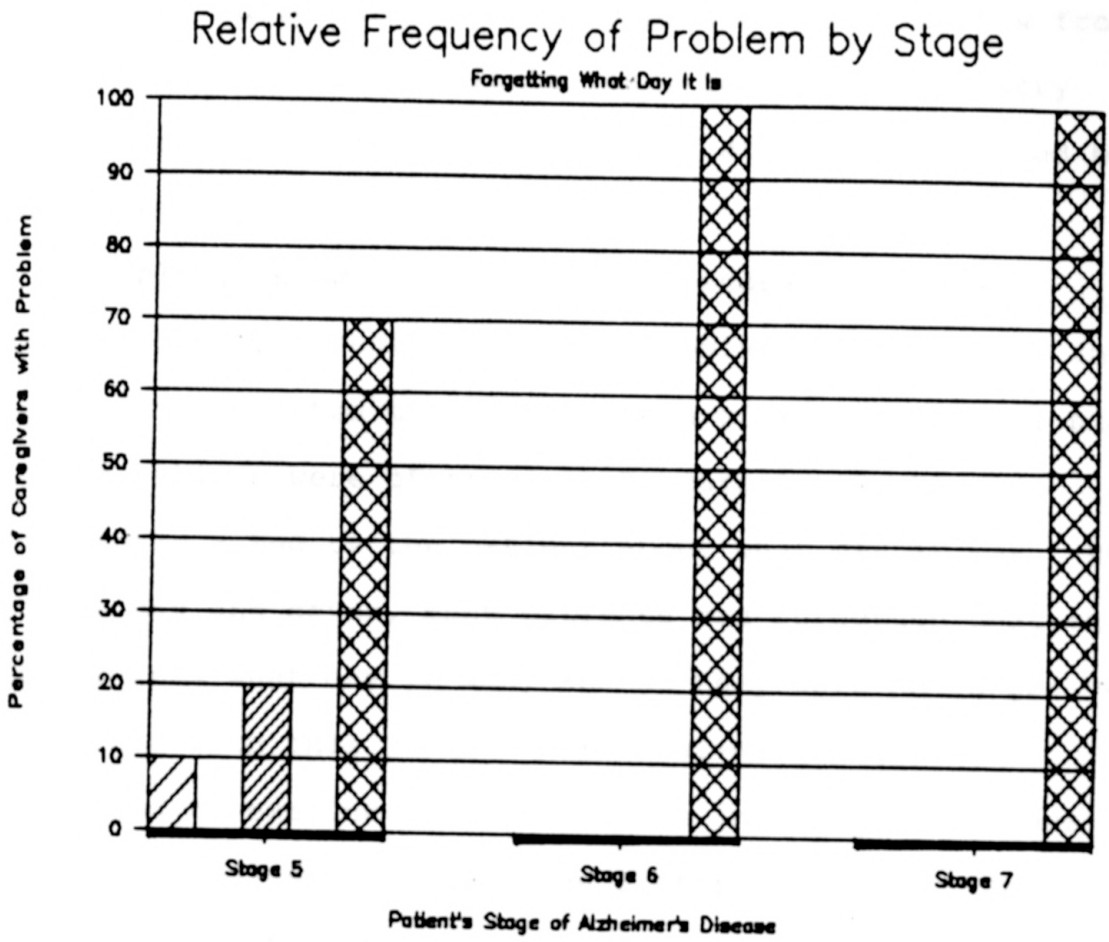
Frequency of Forgetting What Day It Is

The problem of forgetting the date was one of the most frequent memory and behavior problems. In stage five, 70% of the caregivers reported that they were confronted by this problem daily or more often (see Figure 12). By stages six and seven all of the caregivers reported that this problem occurred daily or more often. One explanation for the high frequency of this problem may be because the loss of short-term memory is one of the first symptoms of Alzheimer's disease.

Stress Associated with Forgetting What Day It Is

The frequency of forgetting the date was not significantly correlated with the stress associated with this problem by the caregiver ($r=0.19$, $p=.16$). However, this problem may be more stressful for both the caregiver and the patient in the early stages of Alzheimer's disease, because patients in these stages often are aware that

Figure 12



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

something is wrong with their memories. Patients respond to this problem differently: some patient's get very angry and defensive, while others become depressed and withdraw from activities. How the patients react to their own memory impairments can affect the amount of stress experienced by the caregivers.

Table 16 shows the mean stress scores by stage experienced by caregivers. The caregivers of patients in stage five reported the highest mean of stress. These high stress ratings were often given by caregivers who were frequently asked by the patient about what day it was. By stages six and seven, most patients had forgotten that they didn't know what day it was, and so they were no longer very concerned with this issue. A Kruskal-Wallis test was conducted to examine the differences in caregiver stress between caregivers in the three different stages. The results were statistically significant (H^1=7.09, k=3, $\underline{n}$=27, $\underline{p}$>.05).

Caregiver Control: Forgetting What Day It Is

The amount of stress associated with the forgetting the date was not significantly correlated with the amount of control associated with this problem by the caregiver (r=-0.007, $\underline{p}$=.49). According to Figure 13, throughout the last three stages of Alzheimer's disease, an overwhelming majority of the caregivers perceived that they had extensive

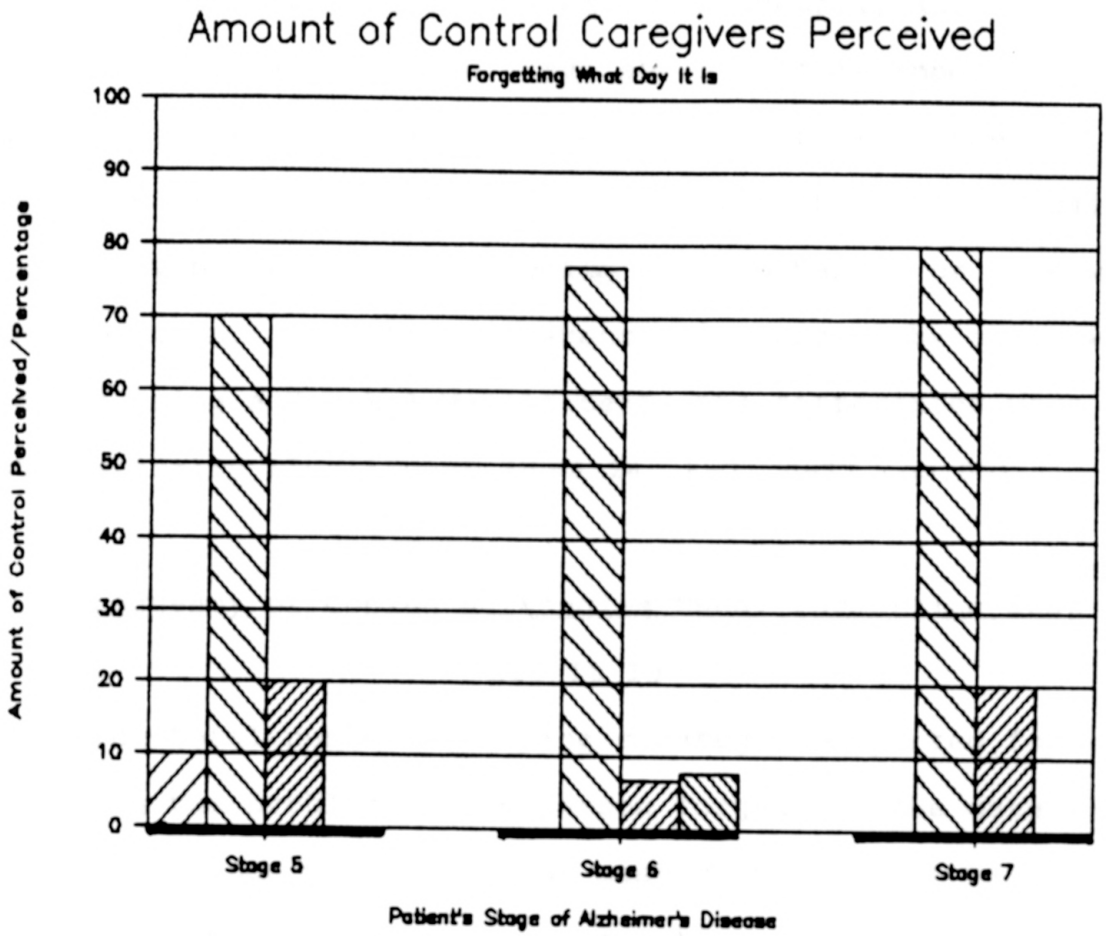
Table 16

Amount of Stress Perceived by Caregivers Forgetting What Day It Is

Stage	M	SD	Range
5	4.44	3.47	1-10
6	2.08	2.56	1-10
7	2.20	2.68	1-7
All Stages	2.82	2.98	1-10

n=28

Figure 13



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

control over handling the problem of the person forgetting what day it was. In stage five, 70% of the caregivers reported that they felt they had such control, and this percentage rose to 80% in stage seven. It is important to note that these caregivers were not able to keep the patients from forgetting what day it was, but they perceived that they had control over being able to handle or cope with this problem. When the differences in control by stage were tested using a Kruskal-Wallis test, the differences were statistically significant (H^1=8.24, k=3, $\underline{n}$=27, $\underline{p}$>.05).

Frequency of Coping Strategies Used: Forgetting What Day It Is

The total number of coping strategies reported for handling the problem of the person forgetting the date was 32. Acceptance was by far the most common way of handling this problem (see Table 17), accounting for almost 70% of all the coping strategies reported. When caring for a person with Alzheimer's disease, there are many complex and difficult problems that require the caregiver's constant and immediate attention. Thus, the caregiver may often have only enough time and energy to be concerned with providing for the patient's basic needs and trying to handle life threatening problems. Caregivers may soon realize that the person's forgetting the date is a minor problem, since it does not put the patient in any physical danger or create

Table 17

Rank Order of Coping Strategies Used Forgetting What Day It Is

Coping Strategy	Percentage Used	
Acceptance	69%	(n=22)
Direct Action	25%	(n=8)
Environmental Intervention	3%	(n=1)
Social Support	3%	(n=1)
Situation Redefinition	0%	(n=0)
Catharsis	0%	(n=0)
Relaxation	0%	(n=0)
Religion	0%	(n=0)

n=28

great emotional discomfort for the caregiver.

Frequency of Environmental Intervention: Forgetting What Day It Is

Although environmental intervention was used very little, it was still tied with social support for the third most frequent coping strategy for handling this problem. A Kruskal-Wallis test was employed to examine the differences in environmental management used by caregivers of the patients in the last three stages of Alzheimer's disease. The results were not statistically significant (H^1=3.86, k=3, $\underline{n}$=27).

The environmental interventions reported by caregivers when questioned in detail included the following: putting up big calendars and marking the days off as they passed, having the patient look at the newspaper and writing down the date, encouraging the patient to look at the date on their watch, and writing out a daily schedule ("The day is____. The month is___. The schedule for today is____."). A total of 12 environmental intervention were employed by caregivers. Of those tried by the caregivers only 14% of them were reported by the caregivers to have been successful. One reason for this limited success is that the environmental interventions listed above can only work while the patient is still able to read and understand what the words and numbers mean.

Destroying Property

Destroying property can be accidental, such as the memory-impaired person tripping over the coffee table and knocking something off, or it can be the result of aggressive and agitated behavior. For example, if the patient wants to get out of a locked door, the patient may become upset and agitated and may begin to kick and hit the door or the surrounding walls.

People with Alzheimer's disease are not able to adequately evaluate the consequences of their own actions. They may attempt to do fairly common tasks, but no longer have the skills or the proper judgment necessary to complete the tasks safely. As a result, accidents can happen easily. Accidents are also more likely to occur when a caretaker is angry, tired, upset, or in a hurry. The person suffering from Alzheimer's disease may misinterpret these feelings and have a catastrophic reaction, perhaps causing an accident. When an accident occurs, not only can the patient or others be hurt, but there also can be damage to the home and to it's contents. A total of 67% of the caregivers said that they had at some time been confronted by this problem. The mean stress rating for the problem of destroying property was 3.75 (SD=2.55), which was below the median stress score of 4.26 for all of the memory and behavior problem experienced by caregivers. Scores ranged from 1 to 8.

Frequency of Destroying Property

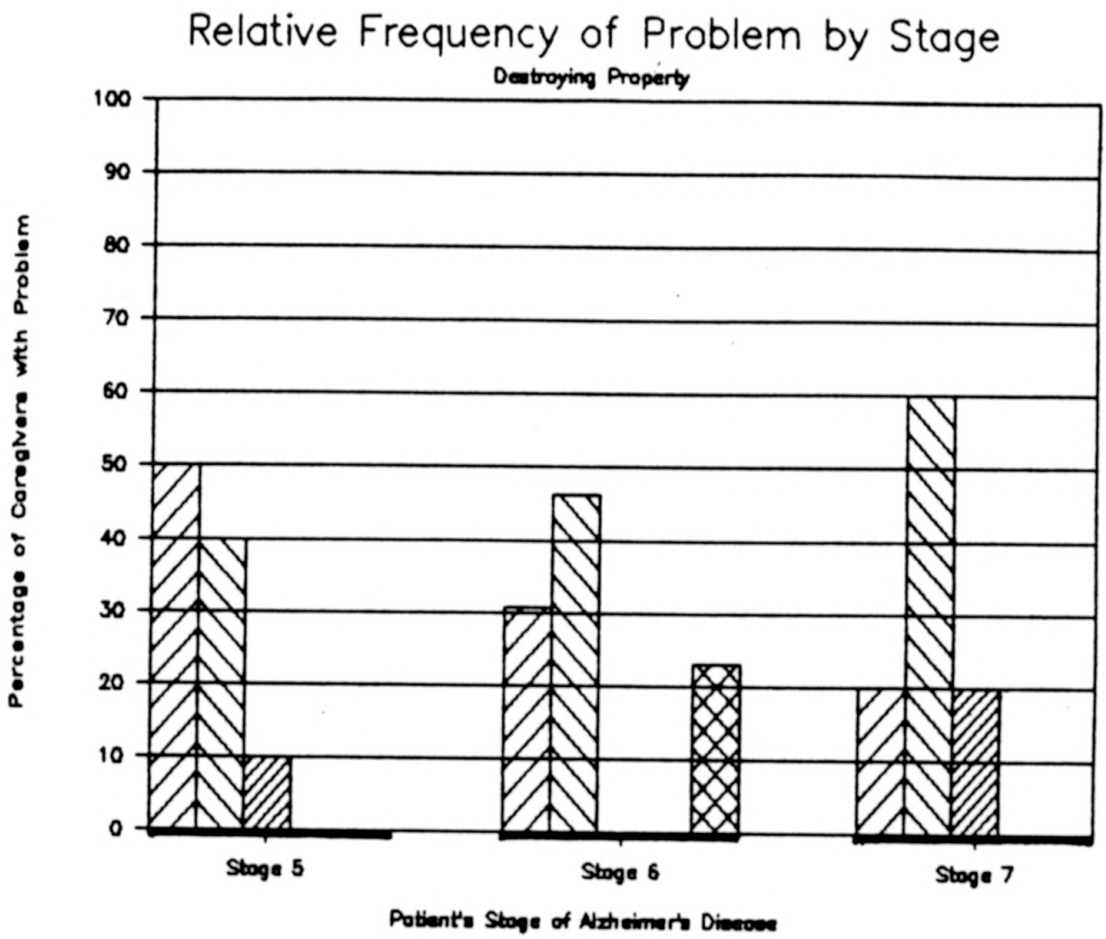
The problem of destroying property was one of the least frequent memory and behavior problems that caregivers confronted. Most of these caregivers reported that this problem had not occurred during the week of the interview.

As shown in Figure 14, this problem occurred occasionally throughout the last three stages of Alzheimer's disease. This problem occurred most frequently during stage six. Here 23% of the caregivers reported that this problem occurred daily or more often.

Stress Associated with Destroying Property

The frequency of destroying property was not significantly correlated with the stress associated with the problem by the caregivers ($r=-0.03$, $p=.45$). As shown in Table 18, the highest mean stress score by stage reported was 5.40, and was experienced by the caregivers caring for patients in the fifth stage of the disease. Table 18 suggests that the amount of stress reported by the caregivers for this problem may decline as the stages of the disease progress. As the patient's judgement and coordination decline with the progression of the disease, it may become more evident that these destructive actions result from the disease and are not deliberate spiteful acts aimed towards the caregiver. However, when a Kruskal-Wallis test was conducted to examine the differences in stress

Figure 14



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Table 18

Amount of Stress Perceived by Caregivers Destroying Property

Stage	M	SD	Range
5	5.40	2.61	2-8
6	3.80	2.20	1-7
7	3.00	2.83	1-7
All Stages	3.82	2.44	1-8

n=20

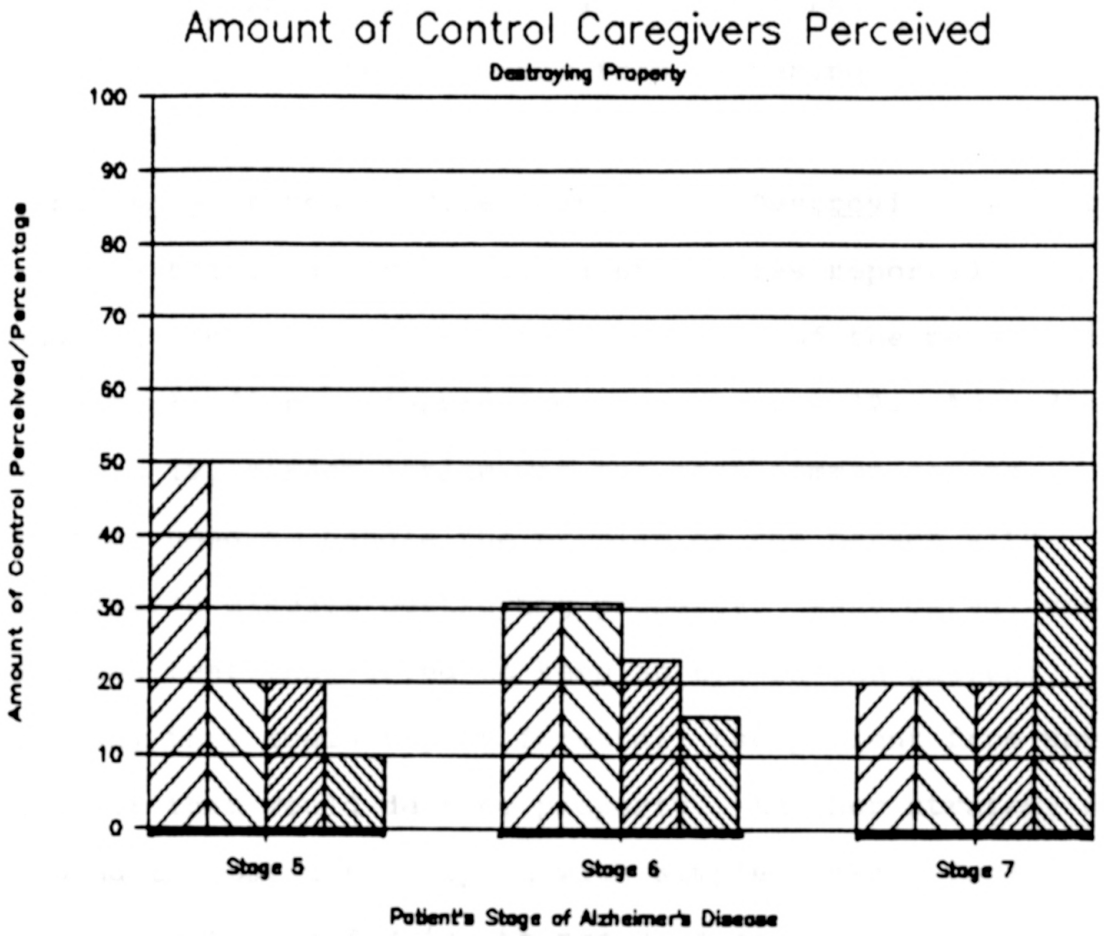
between caregivers of patient's in stages five, six, and seven, the results were not statistically significant (H^1=2.87, k=3, $\underline{n}$=18).

Caregiver Control: Destroying Property

The Pearson Product Moment correlation coefficient between stress and control (r=-0.15, $\underline{p}$=.21) indicated no significant linear relationship between the two variables. According to Figure 15, most caregivers felt that they had some or extensive control in handling the problem of destroying property. The percentage of caregivers who felt they had no control increased as the stages of the disease progressed, with 40% of the caregivers caring for patients in stage seven reporting no control. However, when a Kruskal-Wallis test was employed to explore the differences between the amount of perceived caregiver control by stage of the disease, the results were not significant (H^1=-1.78, k=3, $\underline{n}$=18).

Caregiver reports indicate that the amount of control a caregiver perceived often depended upon what type of property was being destroyed and what events precipitated this behavior. For example, if the patient picked up a vase and accidently dropped it, the caregiver had some control over this problem because he or she could remove objects that could be easily broken from the patient's environment. However, if the patient was sufficiently agitated or angered

Figure 15


Amount of Control Caregivers Perceived
Destroying Property
Amount of Control Perceived/Percentage
100
90
80
70
60
50
40
30
20
10
0
Stage 5
Stage 6
Stage 7
Patient's Stage of Alzheimer's Disease
= Problem doesn't apply
= Quite a lot/complete control
= Some control
= No control

enough to break an object such as a door, the amount of control a caregiver perceives may be lower, unless he or she can identify what caused the catastrophic reactions, and believes it could be prevented from happening again.

Frequency of Coping Strategies Used: Destroying Property

The total number of coping strategies reported for handling the memory and behavior problem of the person with Alzheimer's disease destroying property was 32. According to Table 19, direct action was the most common coping strategy used to handle the problem of the person with Alzheimer's disease destroying property. Many caregivers reported that they tried to keep an eye on the patient. In this way they could try to forestall the patient from any behavior that would destroy property. Another strategy was keeping the patient occupied with simple tasks. Caregivers also tried to avoid doing things that made the patient upset or agitated.

Acceptance and environmental intervention were also commonly used to handle the problem of the patient destroying property. Both were used approximately 19% of the time. Caregivers reported trying to accept that the patients could not control their behavior, and that the caregiver might not always be able to prevent things from being broken. Environmental interventions will be discussed in greater detail later. Situation redefinition and

Table 19

Rank Order of Coping Strategy Used Destroying Property

Coping Strategy	Percentage Used
Direct Action	28% (n=9)
Environmental Intervention	19% (n=6)
Acceptance	19% (n=6)
Situation Redefinition	13% (n=4)
Catharsis	13% (n=4)
Social Support	9% (n=3)
Distraction	0% (n=0)
Relaxation	0% (n=0)
Religion	0% (n=0)

n=20

catharsis were other common coping strategies used while handling this problem. When employing situation redefinition, the caregiver tried to handle the problem of the patient destroying property by trying to see the problem in a different light in order to make it more bearable. For example, a caregiver reported "It is not his fault that he broke my favorite vase. He acted that way because he became confused and upset and was unable to control his reactions." At other times caregivers used catharsis and expressed their emotions in order to handle this problem.

Frequency of Environmental Interventions: Destroying Property

The coping strategy of environmental intervention was reported most frequently by caregivers of patients in stage six, and followed direct action in frequency of use. A Kruskal-Wallis test was employed to examine the differences in environmental management used by the caregivers caring for patients in the three different stages of the disease. The results were statistically significant (H^1=53.84, k=3, $\underline{n}$=18, $\underline{p}$>.05).

When the caregivers were asked to describe their use of environmental intervention for this problem, a total of 18 environmental interventions were reported by caregivers; of those, 89% were reported to have been successful. The most common environmental intervention reported by the caregivers

was removing things from the environment, such as valuable and breakable objects. Objects in the traffic path that could easily be tripped over, such as throw rugs, low stools and coffee tables, also were removed. Caregivers also eliminated things that could be dangerous, such as chairs or tables with sharp edges, pictures with glass, guns, knives, medicines, poisonous plants, and flammable or toxic substances. Small things that patients could put into their mouths also were removed. For example, one patient would pull the buttons off of her clothing and put them in her mouth. The caregiver had to replace the buttons with zippers or draw strings. Providing sturdy furniture or fastening the objects securely down was another environmental intervention used by the caregivers. For example, for one patient who kept knocking a small television off of its stand, replacing the small television stand with a console television could have eliminated this problem. Securely fastened handrails were reported to be helpful in stairwells and bathrooms. The environmental interventions listed above fit into Pynoos and his associates' (1988) environmental management strategies of removing or modifying objects and simplifying tasks and the environment.

Waking the Caregiver Up at Night

Memory impaired persons quickly loose the ability to

keep track of the passage of time because they have difficulty remembering the immediate past. As a result, they can't remember if they have been in bed for ten minutes or eight hours. A total of 87% of the caregivers interviewed were at some time confronted by the problem of the person with Alzheimer's disease waking them up at night. This problem was the fifth most stressful problem experienced by the caregivers, with a mean stress score of 4.46 (SD=3.18), with scores ranging from 1 to 10.

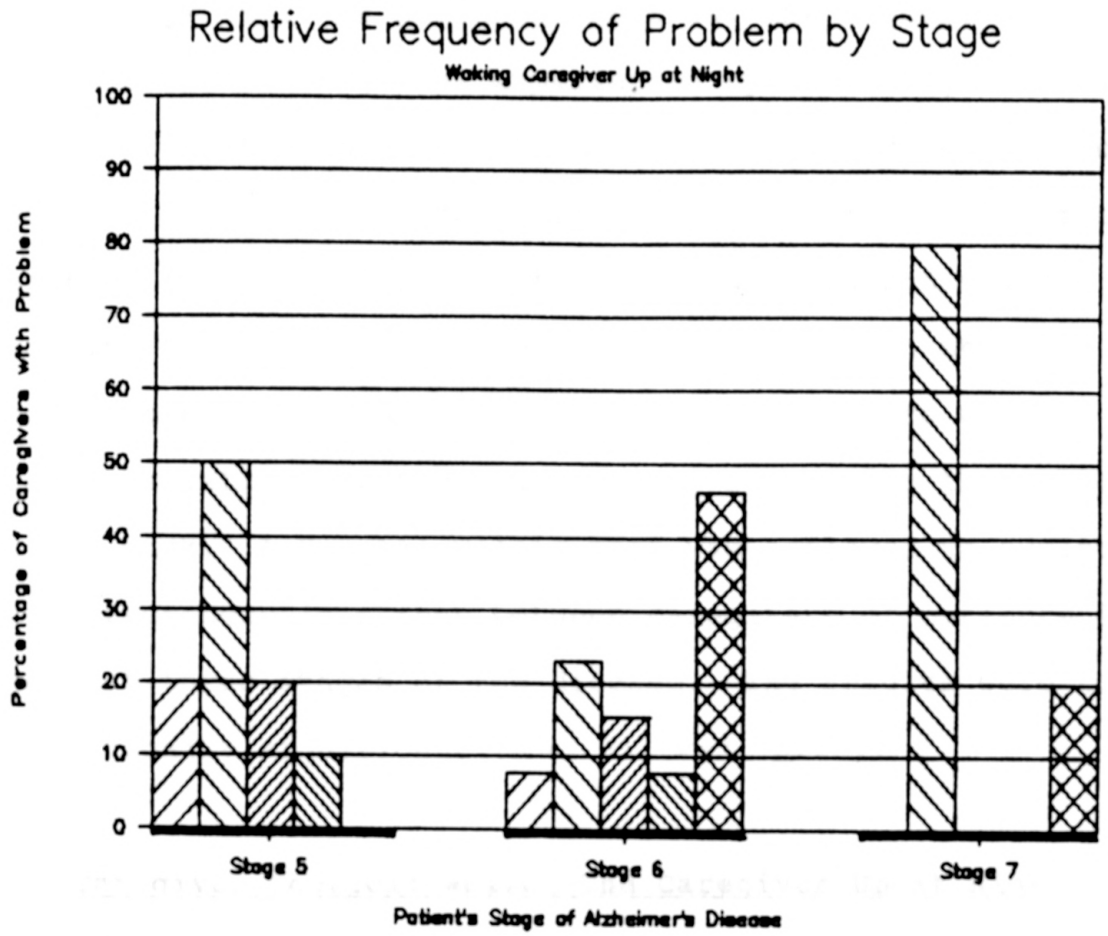
Frequency of Waking Caregiver Up at Night

The problem of waking the caregiver up at night was the sixth most frequent of all of the problems. According to Figure 16, this problem occurred most frequently in the sixth stage of the disease. In the fifth stage, 50% of the caregivers reported that the problem had occurred but not in the past week, and none reported it as a daily event. However, in stage six the problem occurred more often during the course a week than in any other stage. Here, 46% of the caregivers reported that the problem occurred daily or more often. In stage seven, the frequency of the this problem declined, and 80% of the caregivers reported that the problem had not occurred in the past week.

Stress Associated with Waking Caregiver Up at Night

The correlation between the frequency of waking the

Figure 16



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

caregiver up at night and the stress associated with this problem by the caregivers was not statistically significant ($r=0.20$, $p=.15$). As shown in Table 20, the highest mean stress score by stage was experienced by the caregivers caring for patients in the fifth stage of the disease, who reported a mean stress score of 5.63. The amount of stress reported by caregivers declined in stages six and seven, dropping to a mean of 2.60 by stage seven. High stress scores were often reported by caregivers who were worried about the patient destroying property or hurting themselves in the dark. A Kruskal-Wallis test was employed to explore the differences in stress between caregivers of patients in the last three stages of the disease. The results were not statistically significant ($H^{l}=3.81$, $k=3$, $n=25$).

Caregiver Control: Waking The Caregiver Up at Night

The correlation between stress and control ($r=-0.17$, $p=.46$) for the problem of the patient waking the caregiver up at night did not indicate a significant linear relationship between the two variables. Figure 17 also suggests that there are no patterns by stage in the amount of control caregivers perceived in handling the problem of the patient waking them up at night. When the differences in control by stage were examined using a Kruskal-Wallis test, the differences again were not statistically significant ($H^{l}=-1.65$, $k=3$, $n=25$). The amount of control

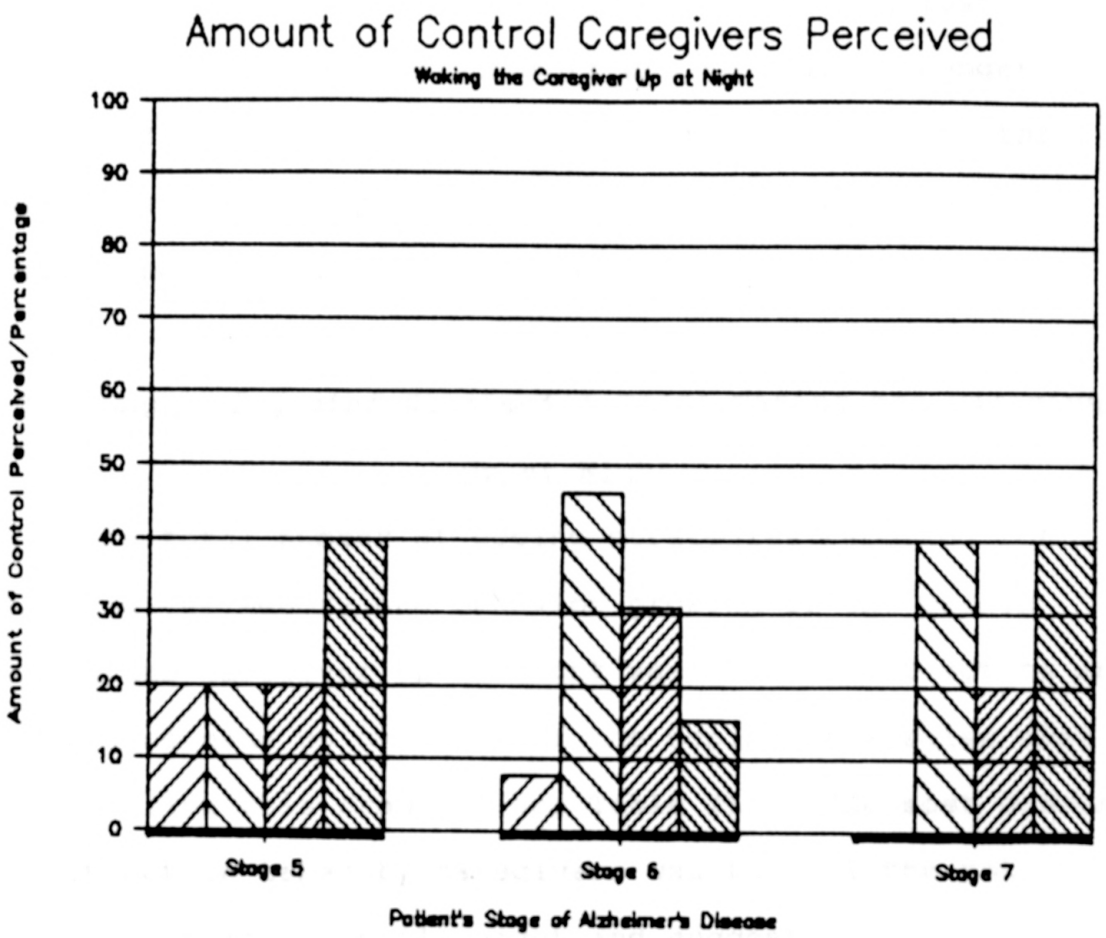
Table 20

Amount of Stress Perceived by Caregivers Waking the Caregiver Up at Night

Stage	M	SD	Range
5	5.63	2.39	2-10
6	4.75	3.31	1-10
7	2.60	3.58	1-9
All Stages	4.46	2.90	1-10

n=26

Figure 17



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

caregivers perceived that they had over this problem may have depended upon the reasons the person became restless (e.g., needing to use the bathroom and becoming lost or confused in the dark, discomfort due to cold or hunger, etc.). If the caregivers were able to identify why the person was waking up at night, they often reported perceiving more control over handling this problem.

Frequency of Coping Strategies Used: Waking the Caregiver Up at Night

The total number of coping strategies reported for handling the memory and behavior problem of the person waking the caregiver up at night was 48. Direct action and acceptance made up over 70% of the coping strategies used for handling this problem (see Table 21). The most common direct action taken by caregivers was to tell the patient calmly that it was still night and suggest going back to bed. One caregiver found that if she let the patient wander around for a little while before she tried to coax him back to bed, he was more cooperative. Other caregivers found the patients slept better at night if they were prevented from napping during the day. Making sure the patient was active or got some exercise during the day also was reported to be helpful.

Table 21

Rank Order of Coping Strategies Used Waking the Caregiver Up at Night

Coping Strategy	Percentage Used	
Direct Action	38%	(n=18)
Acceptance	33%	(n=16)
Environmental Intervention	15%	(n=7)
Social Support	6%	(n=3)
Situation Redefinition	4%	(n=2)
Catharsis	4%	(n=2)
Distraction	0%	(n=0)
Relaxation	0%	(n=0)
Religion	0%	(n=0)

n=26

Frequency of Environmental Intervention: Waking The Caregiver Up at Night

Environmental intervention was the third most common coping strategy reported for handling the problem of the patient waking the caregiver up at night. A Kruskal-Wallis test was employed to examine the differences in environmental management used by the caregivers caring for patient's in the three different stages of the disease. The results of the analysis were not statistically significant (H^1=1.27, k=3, $\underline{n}$=25).

Throughout the course of the disease, the most common environmental intervention caregivers tried was placing a nightlight in the patient's bedroom and/or in the bathroom yo help the patient with orientation. A nightlight also helped the patient find his or her way to the bathroom, and helped prevent the patient from tripping over or bumping into things in the dark. When the caregiver was a spouse, many couples got separate beds or moved into separate bedrooms to keep from disturbing each other's sleep. This intervention fits Pynoos and his associates' (1988) environmental management strategy of restricting or changing areas.

Introducing environmental modifications was another one of Pynoos and his associates' environmental management strategies that described many of the environmental interventions reported by the caregivers. For example, in

order for the caregiver to hear when the patient was up at night, many caregivers would leave the bedroom doors open or use an intercom system (such as those designed for monitoring infants). One caregiver tied a rope with a bell on it from the headboard to the footboard so that she could hear the patient get out of bed.

Some caregivers found that getting a hospital bed or adding bars to the patient's bed helped keep the patient in bed at night. However, bars have to be used with caution because some patients try to climb over the bars and might fall or get caught up in the bars. Other caregivers found that a short-term strategy was keeping a port-a-potty next to the patient's bed or using a clock with big numbers. Once the patient forgot how to use the port-a-potty and how to tell time these strategies were not very helpful. When these and other methods failed, some caregivers used medication or physical restraints to help the patient sleep at night or stay in bed. Physical restraints helped with some patients, but other caregivers found that the use of physical restraints made the patient even more upset and angry. The use of physical restraints should be limited and used only as a last resort. When caregivers were questioned in detail about environmental interventions they reported employing a total of 41 environmental interventions; of those, 92% were reported to have been successful.

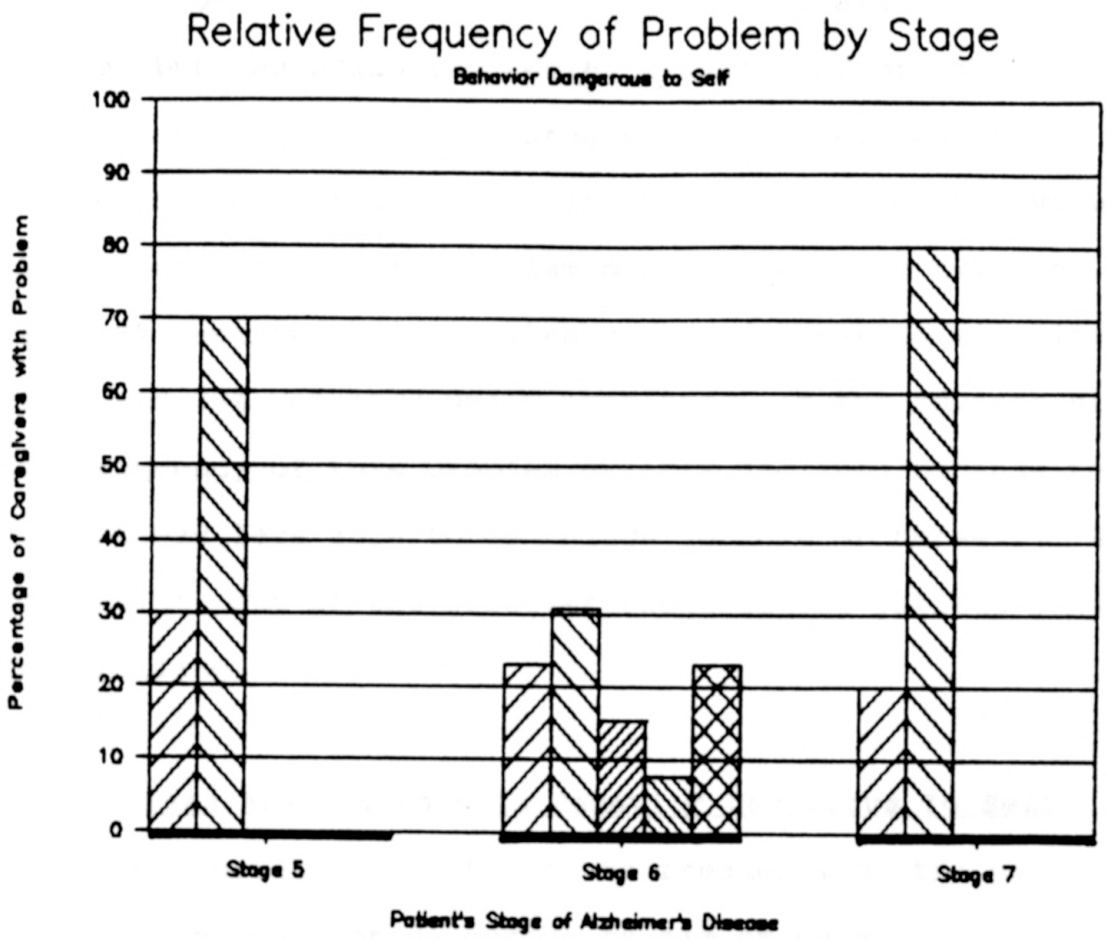
Engaging in Behavior Dangerous to Self

When a person's skills, abilities, and judgement decline because of Alzheimer's disease, everyday activities and tasks can become very dangerous. As the person becomes less aware of the danger in the environment, behaviors such as driving, shaving, or operating tools and appliances he or she has been using for many years can become very dangerous. Unfortunately, as the patient's condition declines, so will the number of things which can be done alone safely. A total of 70% of the caregivers interviewed were at some time confronted with the problem of the patient engaging in behavior dangerous to himself or herself. The mean stress rating for the problem of the patient engaging in behavior dangerous to self was 4.95 (SD=3.50), and was the most stressful memory and behavior problem experienced by caregivers (see Table 9).

Frequency of Behavior Dangerous To Self

The frequency of the problem of the patient engaging is behavior dangerous to self was ranked ninth, and was tied with the frequency of the problems of seeing or hearing things, and difficulty toileting self (see Table 8). As shown in Figure 18, in the fifth stage of Alzheimer's disease, 70% of the persons with Alzheimer's disease had at some time engaged in behavior dangerous to him or herself. However, these caregivers reported that this problem

Figure 18



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

typically had not occurred in the week of the interview. This problem was most frequent in stage six (reported by 77% of caregivers) while the patient was still ambulatory and active, but there was increasing evidence of brain damage. In this stage, 31% of the caregivers reported that the problem had occurred but not in the week of the interview, 15% reported that this problem occurred once or twice a week, 8% reported this problem occurred three to six times a week, and 23% reported daily problems. In the seventh stage the frequency of this problem greatly declined because the patient was less able to do things for him or herself. At that point, one of the greatest risks to the patient came from falling.

Stress Associated with Behavior Dangerous To Self

The correlation between the frequency of the patient engaging in behavior dangerous to him or herself and the amount of stress associated with this problem did not indicate a significant linear relationship ($r=0.15$, $p=.22$) between the two variables. The amount of stress perceived by the caregivers varied with disability associated with the progressive stages of the disease. As the patient's judgement and abilities declined, the patient's potential ability to hurt him or herself increased until the patient became less mobile.

In the early stages of Alzheimer's disease, the

patients were often still able to safely do many things by him or herself. However, because the progression of the disease varies from person-to-person and from day-to-day, it was very difficult for the caregiver to know what the patient's real capabilities were at any given time.

According to Figure 18, the problem of the person engaging in behavior potentially dangerous to him or herself was reported to occur infrequently in stage five. However, the mean level of stress reported by was relatively high. This finding might be attributed to patients' high potential to seriously hurt themselves. For example, a person in the early stages of Alzheimer's disease may retain enough long term knowledge to get into a car and start it, but may not be able to make safe decisions fast enough to allow them to drive safely. In a later stage of the disease, the patient would be less likely to enter the car and start it.

As the reported frequency of engaging in behaviors dangerous to self peaked in the sixth stage of Alzheimer's disease, so did the level of stress experienced by caregivers (see Table 22). At this stage, most of the patients were still ambulatory and active, but their mental capabilities were severely impaired. The lack of mental reasoning and good judgement put the patient at greater risk of engaging in behavior dangerous to him or herself, thus increasing the amount of stress experienced by the caregivers.

Table 22

Amount of Stress Perceived by Caregivers Behaviors Dangerous to Self

Stage	M	SD	Range
5	4.29	3.04	1-10
6	5.60	3.53	1-10
7	3.33	4.04	1-8
All Stages	4.90	3.28	1-10

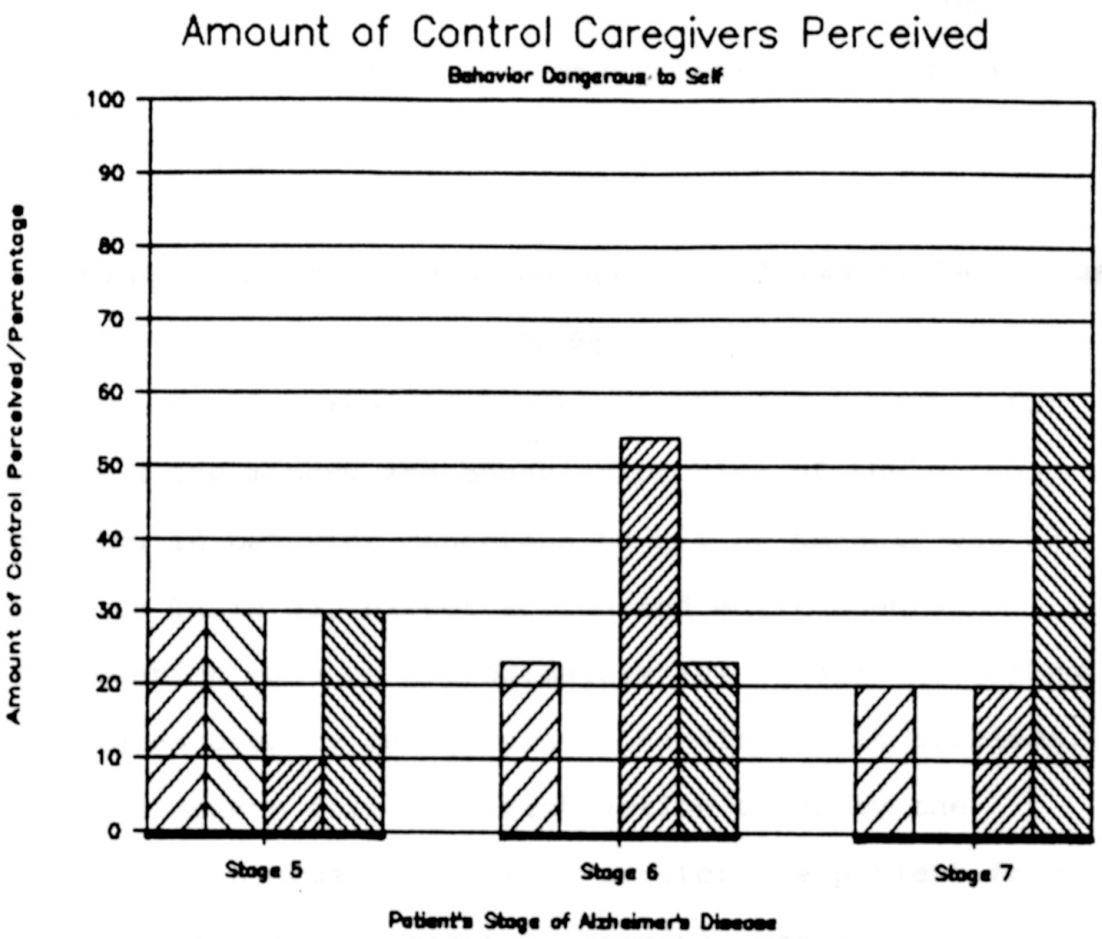
n=21

As more behaviors became too difficult for the patient in stage seven, he or she often became less active. Therefore, the level of stress caused by this problem declined because the patient had less opportunity to engage in behavior that might have been dangerous. However, when the differences in stress by stage were tested using a Kruskal-Wallis test, the results were not significant (H^1=3.83, k=3, $\underline{n}$=21).

Caregiver Control: Behavior Dangerous To Self

The Pearson Product Moments correlation between stress and control (r=-0.39, $\underline{p}$=.02) indicated a significant linear relationship between the two variables. These finding suggest that, the less control caregivers perceived they had over handling the problem of the patient engaging in behavior dangerous to him or herself, the greater their perceived stress. The amount of control the caregivers perceived over handling this problem declined as the stages of the disease progressed. According to Figure 19, in stage five, 30% of the caregivers reported that they had extensive control over this problem, and 10% felt they had some control. In stage six no caregivers reported perceptions of complete control, but approximately 54% of the caregivers reported the perception of some control. The amount of control caregivers perceived they had declined again in the seventh stage of the disease. Here, only 20% of the

Figure 19



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

caregivers felt that they had some control over the problem, while 60% felt that they had no control. A Kruskal-Wallis test was employed to examine the differences in control by stage. The differences were statistically significant (H^1=7.26, k=3, $\underline{n}$=25, $\underline{p}$>.05).

Frequency of Coping Strategies Used: Behavior Dangerous To Self

The total number of coping strategies reported for handling the memory and behavior problem of the person engaging in behavior dangerous to him or herself was 37. As shown in Table 23, direct action and environmental intervention made up approximately 70% of all the coping strategies used by caregivers in handling this problems. The most common form of direct action taken by the caregivers in order to prevent or stop the patient from doing something that might be harmful, was to keep a close and watchful eye on the patient. When activities became too dangerous for the impaired person to do, such as cooking, ironing or running tools and lawn equipment, the caregivers reported that they took over responsibility for those tasks or found someone else to do them.

Smoking and driving were also reported as dangerous behaviors, not only to the patient but for others around them. Caregivers tried to prevent the person from engaging in these behaviors. In the case of driving, some caregivers

Table 23

Overall Rank Order of Coping Strategies Used
Behaviors Dangerous to Self

Coping Strategy	Percentage Used	
Direct Action	38%	(n=14)
Environmental Intervention	32%	(n=12)
Social Support	14%	(n=5)
Acceptance	5%	(n=2)
Catharsis	5%	(n=2)
Distraction	3%	(n=1)
Situation Redefinition	3%	(n=1)
Relaxation	0%	(n=0)
Religion	0%	(n=0)

n=21

had a doctor suspend the patient's license, or disengaged the spark plugs or a similar car part that the caregiver could easily fix, and told the patient that the car didn't run anymore. With regard to smoking, caregivers reported they took away or hid all cigarettes and matches and did not buy anymore.

Frequency of Environmental Intervention: Behavior Dangerous To Self

Environmental intervention was the second most frequent coping strategy employed for the problem of the patient engaging in behavior dangerous to him or herself. A Kruskal-Wallis test was used to examine the differences in environmental management used by caregivers caring for patients in the three different stages of the disease. The results were not significant (H^1=-0.27, k=3, $\underline{n}$=21).

Of all of the problems caregivers confronted, they reported the most environmental interventions for the problem of the patient engaging in behavior dangerous to him or herself. A total of 44 environmental interventions were attempted, with 98% reported to have been successful. Some of the most commonly reported environmental interventions when dealing with this problem included turning off the circuit breaker to the stove and oven and unplugging other kitchen appliances such as the dishwasher, garbage disposal, or toaster when they were not in use. Other ways of

preventing the patient from being hurt while cooking were to hide the pots and pans or to remove the knobs from the stove. In order to prevent the patient from being hurt shaving, many of the caregivers replaced the patient's razor blades with an electric razor. Most of the environmental interventions employed by the caregivers fall into Pynoos and his associates' strategies of removing or modifying objects and introducing environmental modifications.

Caregivers reported that it was also important to remove or securely lock away guns, knives, dangerous tools, and toxic substances. Caregivers suggested that if a patient became upset because he or she thought that his or her guns were missing or stolen, it might make it easier to leave the guns in their usual place. In this case, it was very important that the guns were stored safely and that all ammunition was securely locked away. Another option reported was to remove the firing pin from the gun, so that it could not be fired.

Engaging in Behavior Dangerous to Others

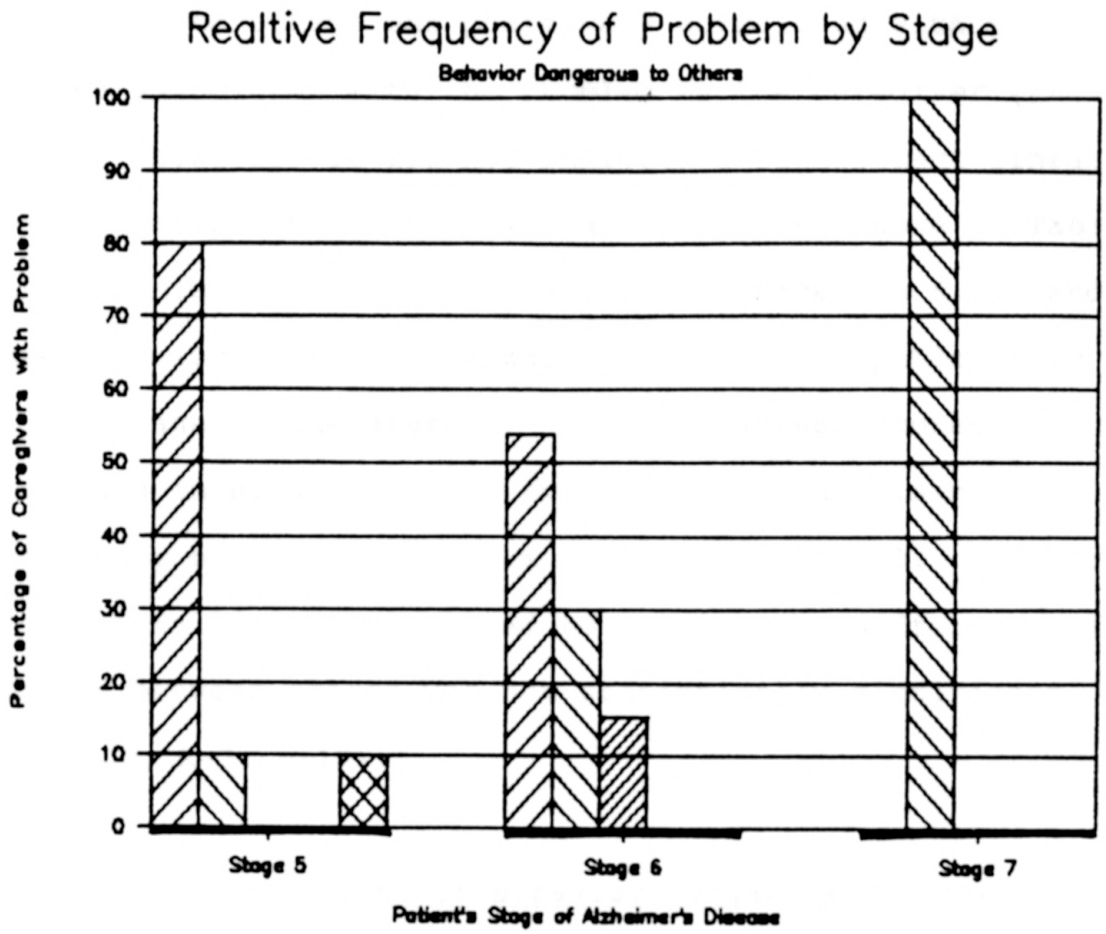
Because the person with Alzheimer's disease can not adequately evaluate the consequences of his or her actions, many everyday activities not only present potential danger to the patient and to the home, but also to those who live with or care for the patient. For example, if the patient spills some water on the floor and forgets to wipe it up,

someone else walking into the room may slip and fall. Other times a patient may become overwhelmed or confused by a situation and overreact angrily or violently. The person may throw things or try to hit, push or bite the caregiver. Approximately 43% of the caregivers interviewed were at some time confronted by the problem of the patient engaging in behavior dangerous to others. The mean stress rating for this problem was 4.31 (SD=2.84) with scores ranging from 1 to 10. This score was just above the median stress score of 4.26 for all of the memory and behavior problems.

Frequency of Behavior Dangerous To Others

The problem of the person with Alzheimer's disease engaging in behavior dangerous to others was the least frequent memory and behavior problem experienced by the caregivers interviewed. Many of the caregivers reported that the problem had occurred, but not in the week of the interview (50%). According to Figure 20, the number of caregivers who had been confronted by this problem increased dramatically as the disease progressed. In stage five, only 10% of the caregivers reported that the problem had occurred. This percentage rose to about 30% in stage six. By stage seven, all (100%) of the caregivers reported that they were at some time confronted by this problem.

Figure 20



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Stress Associated with Behavior Dangerous To Others

The frequency of the patient engaging in behaviors dangerous to others was positively correlated with the stress associated with the problem by the caregiver ($r=0.03$, $p=.44$), however, it did not indicate a significant linear relationship between the two variables. As shown in Table 24, the highest mean stress scores by stage was 6.00, and was experienced by the caregivers caring for patients in the fifth stage of the disease. The mean stress scores declined in stages six and seven despite the rising frequency of the problem, as shown in Figure 20. However, a Kruskal-Wallis test employed to examine the differences in stress between stages was not statistically significant ($H^1=2.00$, $k=3$, $n=12$).

Caregiver Control: Behavior Dangerous To Others

The Pearson Product Moments correlation coefficient between stress and control ($r=0.04$, $p=.41$) indicated no significant linear relationship between the two variables. The amount of control caregivers perceived they had in handling this problem declined as the stages of the disease progressed. Figure 21 shows that in stage five, all of the caregivers who had been confronted by this problem reported extensive control in handling this problem. In stage six, none of the caregivers reported this perception of control in handling the problem, and in stage seven, 60% of

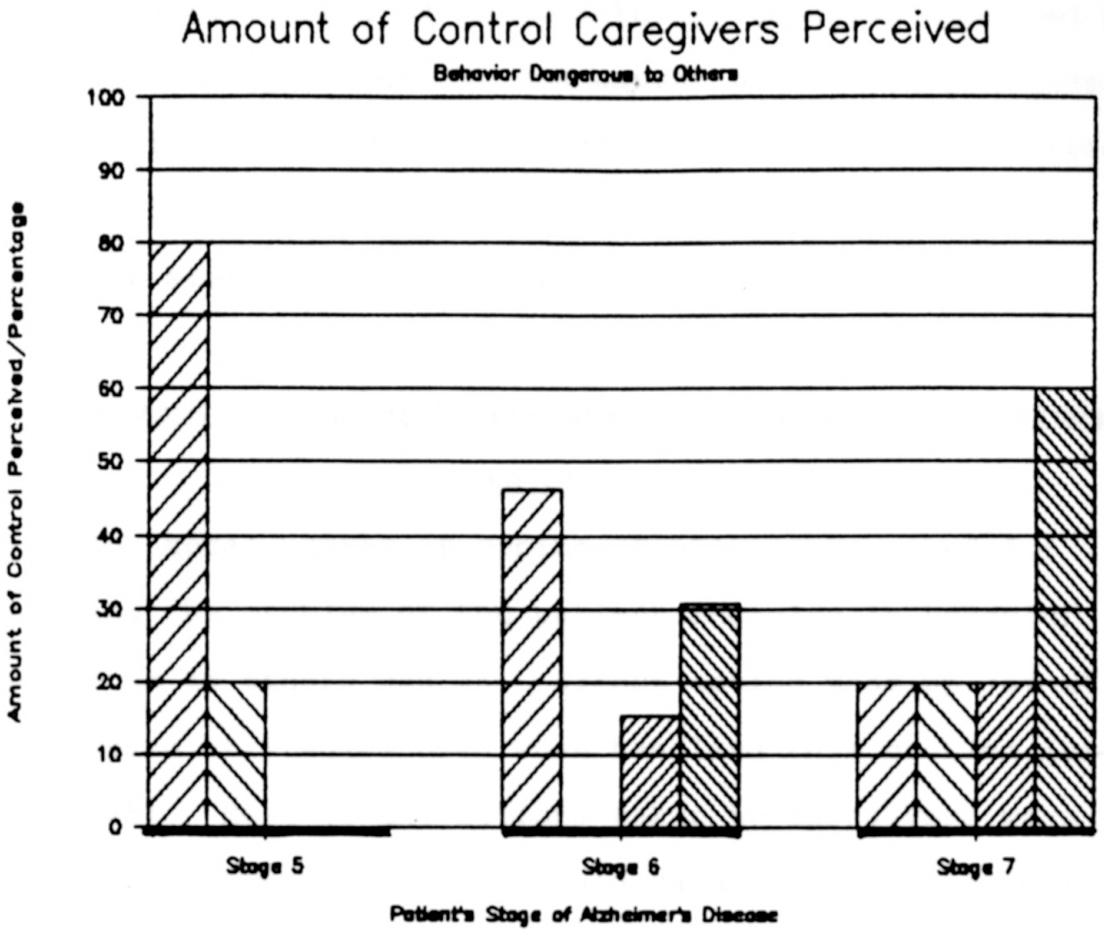
Table 24

Amount of Stress Perceived by Caregivers Behaviors Dangerous to Others

Stage	M	SD	Range
5	6.00	0	6
6	4.67	2.94	1-8
7	2.75	3.50	1-8
All Stages	4.69	3.25	1-8

n=13

Figure 21



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

the caregivers perceived that they had no control in handling the problem of the patient engaging in behavior dangerous to others. A Kruskal-Wallis test was employed to explore the differences in the amount of control perceived by caregivers caring for patients in the last three stages of the disease. The results approached significance but were not statistically significant (H^1=5.96, k=3, $\underline{n}$=12).

Frequency of Coping Strategies Used: Behavior Dangerous to Others

The total number of coping strategies reported for handling the problem of the patient engaging in behavior dangerous to others was 25. Direct action made up 36% of the coping strategies used when handling this problem (see Table 25). Most of the actions taken by caregivers were attempts to prevent accidents and catastrophic reactions from occurring, and were similar to those reported for coping with behavior dangerous to the patient. For example, a caregiver might have offered to drive the patient to the store to prevent the patient from driving. To prevent the patient from becoming overwhelmed by a situation, some caregivers carefully selected what tasks they asked the patient to do or assisted the patient by breaking a large task into smaller steps.

The coping strategies of situation redefinition and acceptance were both used 12% of the time in handling this

Table 25

Rank Order of Coping Strategies Used
Behaviors Dangerous to Others

Coping Strategy	Percentage Used
Direct Action	36% (n=9)
Environmental Intervention	20% (n=5)
Situation Redefinition	12% (n=3)
Acceptance	12% (n=3)
Catharsis	8% (n=2)
Social Support	8% (n=2)
Distraction	4% (n=1)
Relaxation	0% (n=0)
Religion	0% (n=0)

n=13

problem. While the coping strategies of catharsis and social support were both employed 8% of the time. Together they made up 40% of the coping strategies employed for this problem. The coping strategies of situation redefinition, catharsis and social support may have been employed more frequently for this problem because when this problem occurred it often reported to have been frightening and upsetting to the caregiver. Therefore, caregivers may have needed more help in coping with this problem and may have attempted to do so by looking at the problem in a different way, expressing their emotions, or by seeking outside help to assist them in handling these difficult situations.

Frequency of Environmental Interventions: Behavior Dangerous to Others

Environmental intervention was the second most frequent way of handling this problem. However, when the differences in environmental management by caregivers caring for patients in the last three stages of Alzheimer's disease were examined using a Kruskal-Wallis test, the differences were not statistically significant (H^1=1.49, k=3, $\underline{n}$=12).

This problem was very similar to the problem of the patient en gaging in behavior dangerous to him or herself. Therefore, many of the environmental interventions were also similar. A total of 12 environmental interventions were employed by the caregivers, with all (100%) of them reported

to have been successful.

Seeing or Hearing Things

People suffering from dementing illnesses may experience hallucinations. When this happens the person may see, hear or feel things that are not there. These hallucinations are real to the person experiencing them, and can be caused by many different things. The patient may see a reflection in a mirror or reflected from the glass of a window, picture frame, or patio doors and not be able to understand what it is. At night, poor eye sight and shadows can increase the occurrence of hallucinations. Many caregivers reported that the patient would see something on the television and think it was really happening. For example, one caregiver reported that her mother kept telling her that this nice gentlemen, Dan Rather, would come and talk to her every night. At other times the hallucinations may be very distressing or terrifying for the patient. For example, one caregiver reported that her mother called the police because she believed there were three men in her house that wouldn't leave. The three men were images on the television screen. Other hallucinations may make the patient happy or amused. For example, one caregiver reported that his father seemed to have a wonderful time talking to the man in the mirror or talking to his father in the picture on the wall. A total of 70% of the caregivers

interviewed were at some time confronted by the problem of their relative with Alzheimer's disease seeing or hearing things that were not there. The amount of stress associated with this problem was one of the least stressful and was ranked 13th of the 16 problems. The mean stress score reported for this problem was 3.33 (SD=2.31) with scores ranging from 1 to 8.

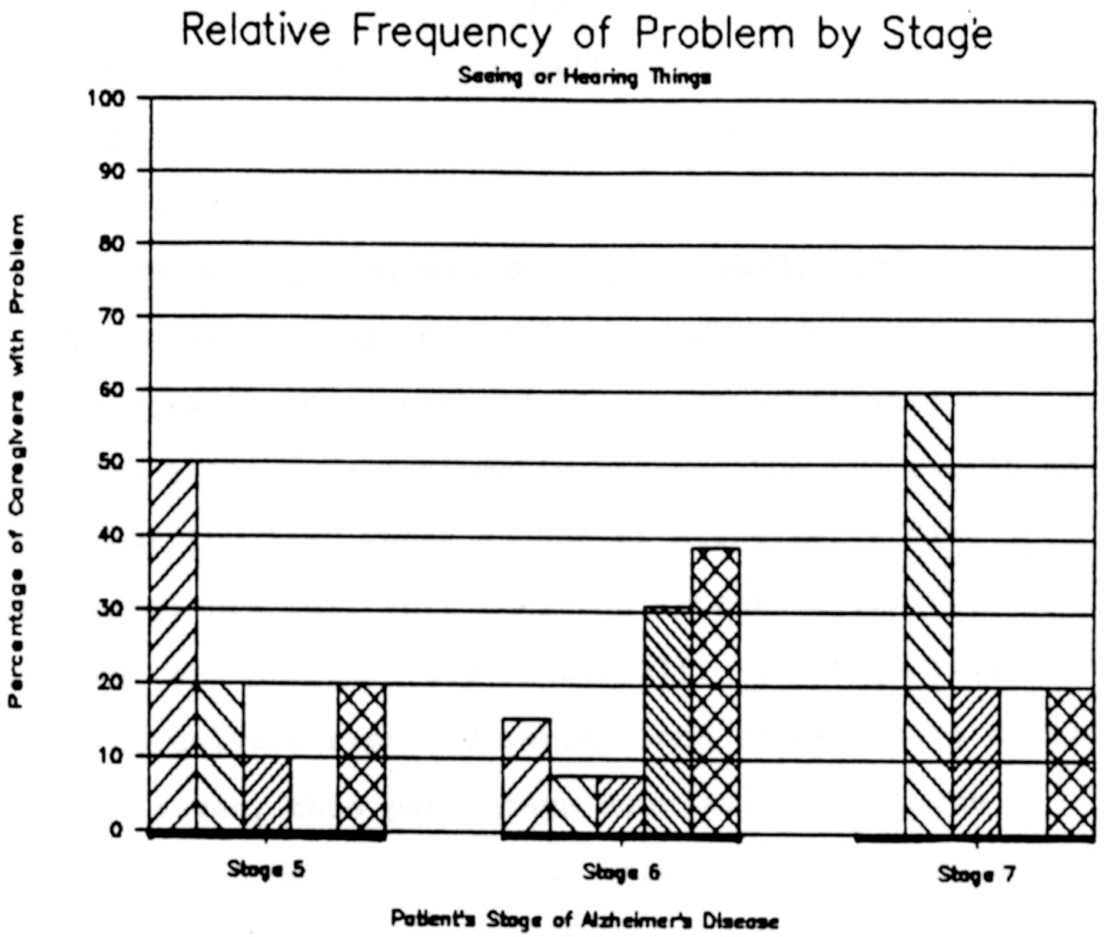
Frequency of Seeing Things or Hearing Things

This problem occurred most frequently in the sixth stage of the disease. According to Figure 22, in the fifth stage, 50% of the caregivers interviewed had not been confronted by this problem. In stage six, not only had approximately 85% of the caregivers reported that this problem had occurred, but this problem was occurring more often during the course of the week than it was in any other stage. In stage seven, all of the caregivers had experienced this problem.

Stress Associated with Seeing or Hearing Things

The correlation between the frequency of seeing or hearing things and the amount of stress associated with the problem of seeing or hearing things ($r=-0.02$, $p=.46$) did not indicate a significant linear relationship between the two variables. The mean stress scores by stage that were associated with this problem by caregivers remained fairly

Figure 22



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

consistent throughout the last three stages of the disease (see Table 26). High stress scores were often associated with hallucinations that occurred frequently or frightened or upset the patient. When the differences in stress by stage were examined using a Kruskal-Wallis test, the differences were not statistically significant (H^1=0.62, k=3, $\underline{n}$=21).

Caregiver Control: Seeing or Hearing Things

The Pearson Product Moments correlation coefficient between stress and control (0.15, $\underline{p}$=.22) indicated no significant linear relationship between the two variables. Throughout the last three stages of Alzheimer's disease, most caregivers felt that they had extensive control over handling this problem (see Figure 23). In stage five, 40% of the caregivers reported perceptions of extensive control. By stage seven, this percentage doubled to 80%. The differences in control by stage were examined using a Kruskal-Wallis test; the results were not statistically significant (H^1=0.65, k=3, $\underline{n}$=21).

Frequency of Coping Strategies Used: Seeing or Hearing Things

The total number of coping strategies reported for handling the memory and behavior problem of the person seeing or hearing things was 32. Acceptance was the most

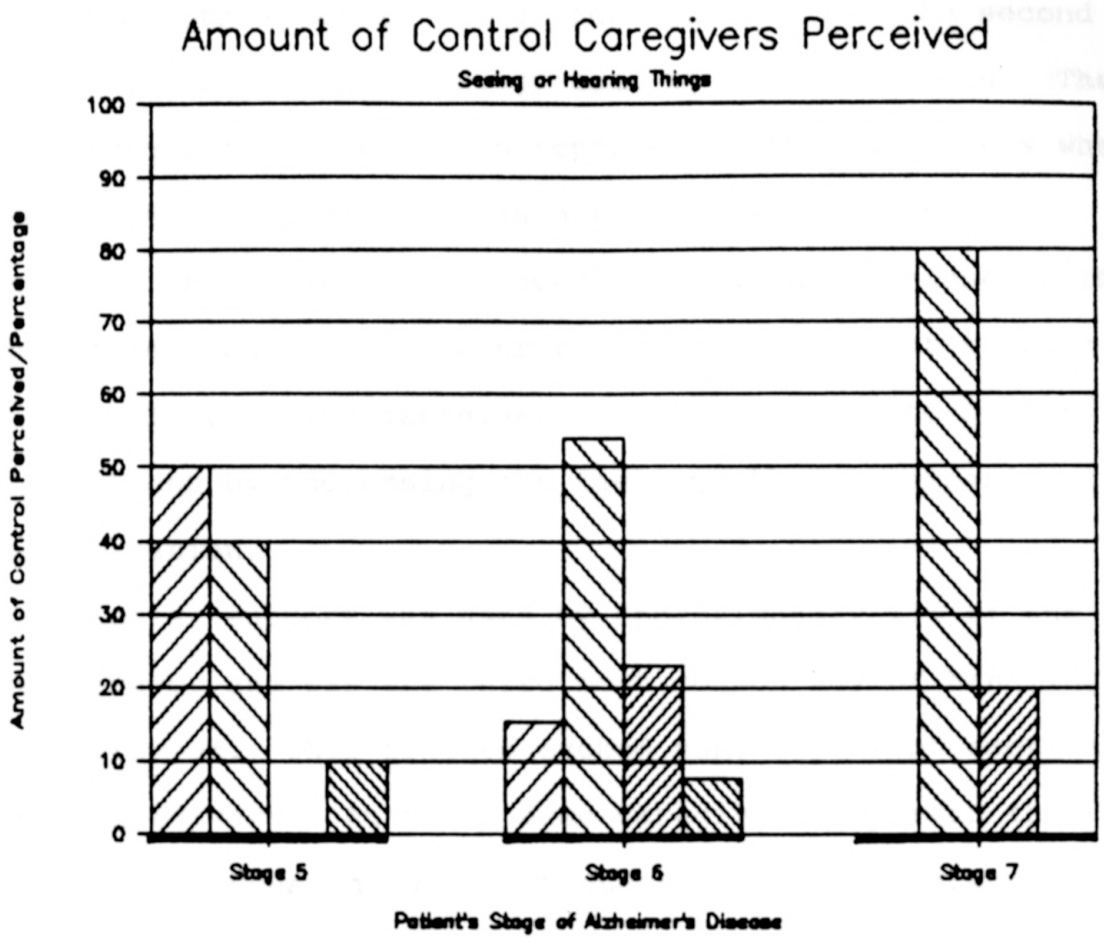
Table 26

Amount of Stress Perceived by Caregivers Seeing or Hearing Things

Stage	M	SD	Range
5	3.80	2.39	1-7
6	2.91	2.02	1-8
7	3.80	3.11	1-8
All Stages	3.33	2.31	1-8

n=21

Figure 23



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

common way of handling this problem of the patient seeing or hearing things, as shown in Table 27. Direct action was reported approximately 31% of the time and was the second most frequent coping strategy used by the caregivers. The most frequent direct action reported by the caregivers when the patient hallucinated was not to disagree with the patient. Many caregivers found that trying to reason with the patient only made the problem and the patient's anxiety worse. Instead the caregivers reported trying to comfort the patient by addressing the feelings that accompanied the hallucination.

Social support was used by approximately 13% of the caregivers, and was the third most common way of handling this problem. This problem evoked many different emotions from caregivers. At times some caregivers reported that it was very distressing while at other times some caregivers found it somewhat humorous. Many caregivers found it helpful to talk about this problem to a relative or a close friend.

Frequency of Environmental Interventions: Seeing or Hearing Things

Environmental intervention was the fourth most common coping strategy employed while trying to handle the problem of the person seeing or hearing things that were not there. The results of the Kruskal-Wallis test employed to examine

Table 27

Rank Order of Coping Strategies Used Seeing or Hearing Things

Coping Strategy	Percentage Used
Acceptance	34% (n=11)
Direct Action	31% (n=10)
Social Support	13% (n=4)
Environmental Intervention	9% (n=3)
Distraction	6% (n=2)
Catharsis	3% (n=1)
Religion	3% (n=1)
Situation Redefinition	0% (n=0)
Relaxation	0% (n=0)

n=21

the differences in environmental management by stages of the disease were not statistically significant (H^1=0.51, k=3, $\underline{n}$=21).

When questioned extensively about the use of environmental interventions a total of 9 environmental interventions were reported by caregivers for this problem, with only 44% of them reported to have been successful. Some of the most common environmental interventions included the following: removing mirrors and pictures covered by glass, shutting the drapes or blinds on doors and windows, leaving night lights on, and controlling when and what the patient watched on television. These environmental interventions are the types of environmental interventions Pynoos and his associates describe in their environmental strategies of removing or modifying objects and providing appropriate environmental and sensory stimulation.

The percentage of successful environmental interventions for this problem was the second lowest of all the memory and behavior problems. Although the environmental interventions above were reported to eliminate or help with this problem some of the time, this problem was perceived to occur no matter what the caregiver tried. Therefore, the success rate reported for environmental interventions were low (33%).

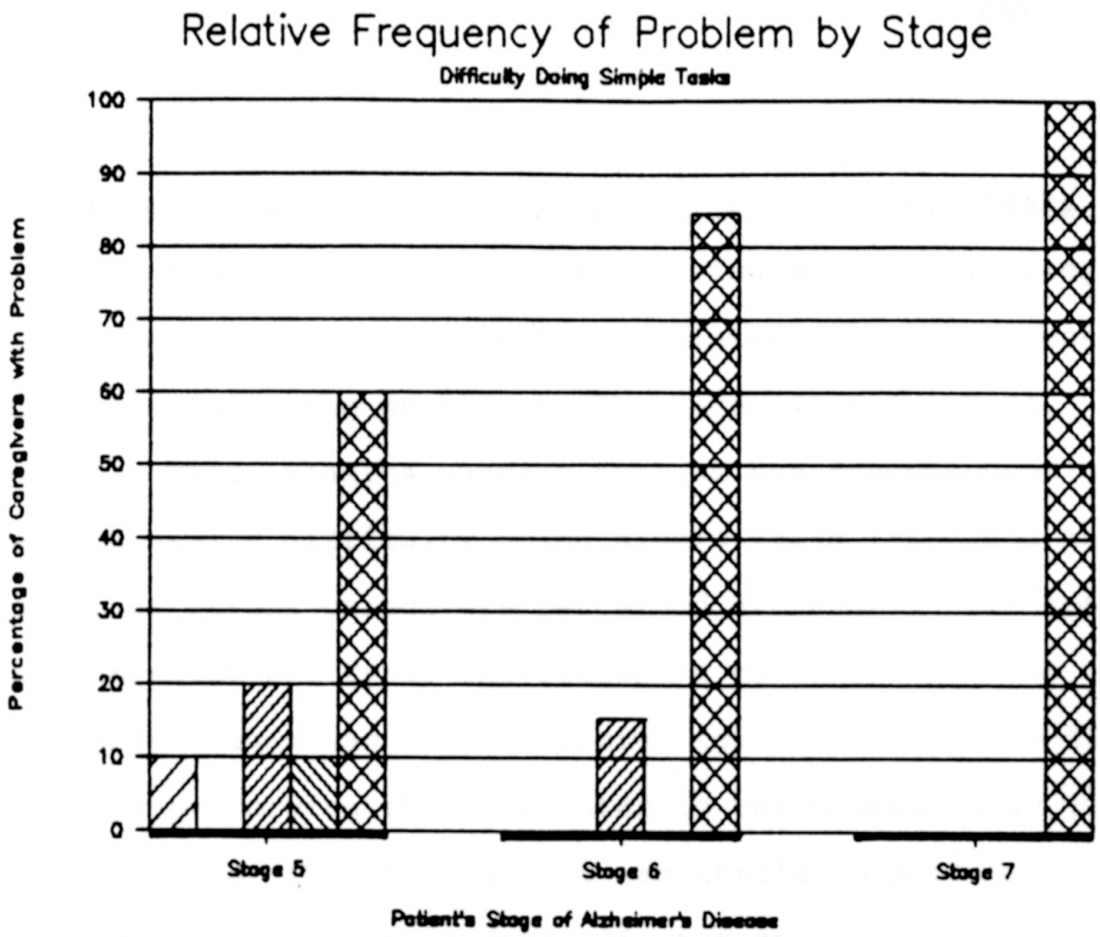
Difficulty Doing Simple Tasks

Gradually losing one's memory means gradually losing the ability to do many things. Memory impairment makes simple activities and tasks very difficult. In the beginning, the patient will start to have difficulty doing tasks such as putting the groceries away, writing checks, or finding the way home from work. As the disease progresses so will the number of things the patients will be able to do for themselves. A total of 97% of the caregivers interviewed reported that they were at some time confronted by this problem. The mean stress score reported by caregivers for the problem of the person having difficulty doing simple tasks was 4.21 (SD=3.05) with scores ranging from 1 to 10, and was close to the median stress score of all the memory and behavior problems (4.26).

Frequency of Difficulty Doing Simple Tasks

The problem of the person with Alzheimer's disease having difficulty doing simple tasks was the most frequent memory and behavior problem caregivers experienced of all the problems. The occurrence of this problem was often one of the first indications that there was something wrong with the person. According to Figure 24, this problem occurred frequently throughout the last three stages of Alzheimer's disease. In stage five, 90% of the caregivers reported that the problem had occurred, and of those, 60% reported the

Figure 24



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

problem occurred daily or more often. The percent of caregivers faced with this problem daily or more often rose to approximately 85% in stage six and to 100% in stage seven.

Stress Associated with Difficulty Doing Simple Tasks

The frequency of the patient having difficulty doing simple tasks was significantly correlated with the stress associated with the problem by the caregivers ($r=-0.34$, $p=.03$). These results suggest that as the frequency of the patient having difficulty doing simple tasks increased the amount of stress caregivers perceived decreased. Perhaps the unpredictability of the patient's current abilities in the early stages was more stressful for the caregivers than actually performing the task later in the disease when it was more clear that the patient was unable to perform the task alone. As shown in Table 28, the mean stress scores by stage experienced by the caregivers remained fairly consistent throughout the last three stages of the disease. High stress scores were often reported by the caregivers who had difficulty accepting the loss of the patient's abilities or those who felt overwhelmed by the accumulation of the patient's responsibilities that the caregiver was forced to assume. When the differences in stress by stage were tested using a Kruskal-Wallis test, the result were not statistically significant ($H^{1}=1.17$, $k=3$, $n=27$).

Table 28

Amount of Stress Perceived by Caregivers
Difficulty Doing Simple Tasks

Stage	M	SD	Range
5	4.22	1.72	2-8
6	4.31	3.50	1-10
7	4.00	4.24	1-10
All Stages	4.21	3.05	1-10

n=29

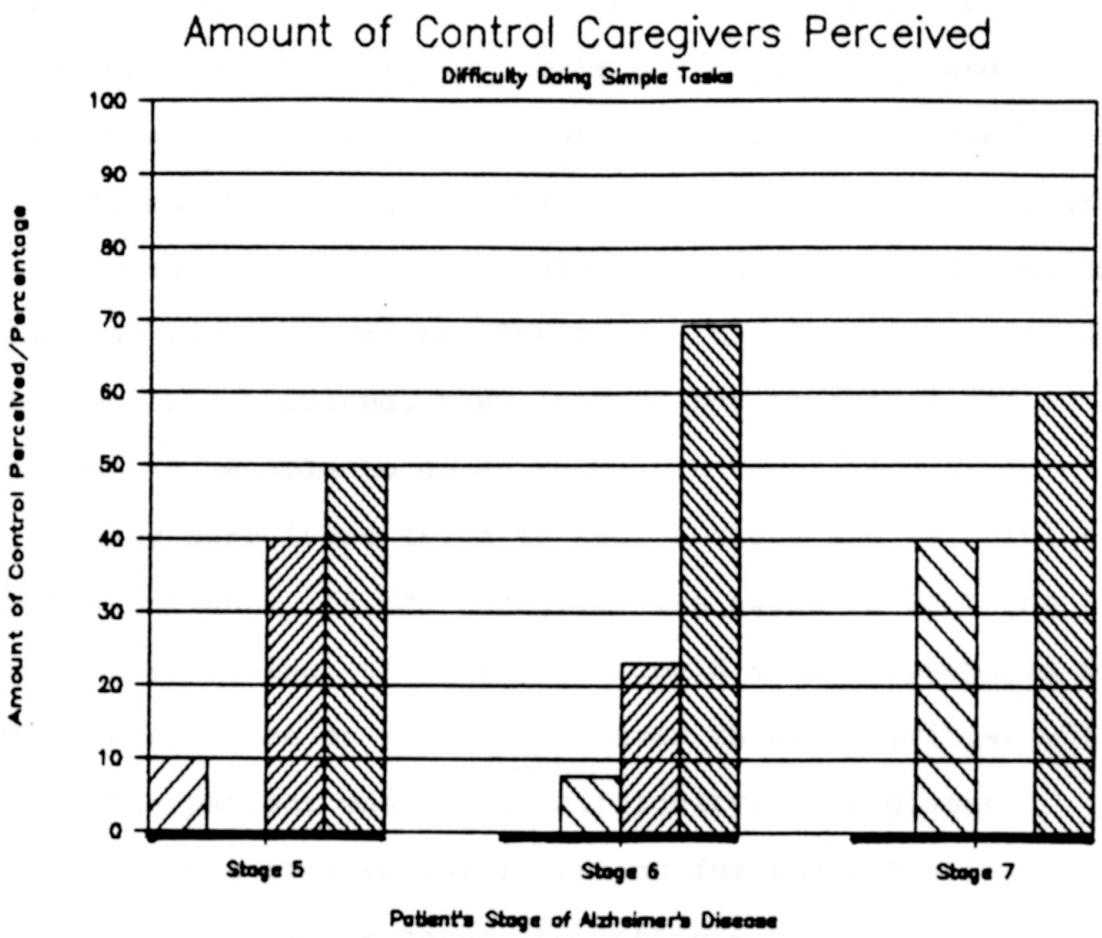
Caregiver Control: Difficulty Doing Simple Tasks

The Pearson Product Moment correlation coefficient between stress and control ($r=-0.21$, $p=.13$) indicated no significant linear relationship between the two variables. Most of the caregivers perceived that they had no control over handling the problem of the person having difficulty doing simple tasks (see Figure 25). Perceptions of no control fluctuated throughout the different stages of the disease. Although more caregivers in each stage perceived they had no control, the number of caregivers who perceived they had extensive control in handling this problem increased as the disease progressed. One reason why the percentage of caregivers who perceived extensive control rose to 40% in stage seven, may be that experiences in coping over the course of the disease provided more time to adjust and find ways to handle the responsibility of the tasks the patient used to do. However, when the differences in control by stage were examined using a Kruskal-Wallis test, the differences were not significant ($H^1=1.53$, $k=3$, $n=27$).

Frequency of Coping Strategies Used: Difficulty Doing Simple Tasks

The total number of coping strategies reported for handling the problem of having difficulty doing simple tasks was 46. Acceptance and direct action made up approximately

Figure 25



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

82% of the coping strategies used by the caregivers coping with this problem (see Table 29). The most common response caregivers gave when asked how they handled this problem was to accept that the patient could not do the task and to help the patient or do it for him or her. As the disease progressed, the caregiver had to assume the responsibility for the tasks the patient could no longer do themselves or they had to find someone else to do it. Caregivers reported that as this happened, they learned not to expect the patient to be able to do as much.

Many caregivers tried to keep a close and watchful eye on the patient. If the caregiver was aware of what the patient was doing, the caregiver could be more prepared to offer assistance or supervision over those activities with which the patient was having difficulty. Caregivers reported that it also was important for the patient's self concept to allow the person to continue to do as much as possible for him or herself. For example, one patient was able to set the table for dinner when the caregiver talked her through each step. The caregiver reported that it made the patient feel good to participate and help, even if it was in a small way. Other caregivers reported that they would let the patient do something even if it was not done correctly, such as wash the dishes, then later the caregiver would go back and redo the task. Other caregivers tried to adjust the task to the patient's current ability. For

Table 29

Rank Order of Coping Strategies Used Difficulty Doing Simple Tasks

Coping Strategy	Percentage Used
Acceptance	43% (n=20)
Direct Action	39% (n=18)
Situation Redefinition	7% (n=3)
Environmental Intervention	4% (n=2)
Social Support	4% (n=2)
Catharsis	2% (n=1)
Distraction	0% (n=0)
Religion	0% (n=0)
Relaxation	0% (n=0)

n=29

example, one caregiver had the patient fold the grocery sacks while the caregiver put the groceries away.

Frequency of Environmental Intervention: Doing Simple Tasks

Environmental intervention was the fourth most common coping strategy employed for this problem. Although environmental intervention made up only a small percentage of coping strategies used, the environmental interventions reported fit into the environmental management strategy suggested by Pynoos and his associates (1988) of simplifying tasks and the environment. In the early stages of the disease, some of the caregivers found it helpful to set things up for the patient's task. For example, when the caregiver wanted the patient to brush his or her teeth the caregiver would lay the tooth paste and tooth brush out and guide the patient through the each step. According to the caregivers, this strategy was usually a short-term solution, because eventually the caregiver had to do the task or hire someone to come in and help. When caregivers were asked to describe their use of environmental intervention for the problem of the difficulty doing simple tasks they reported a total of 10 environmental interventions, with only 70% reported to have been successful.

Difficulty Dressing Self

Many times persons with Alzheimer's disease will refuse

to get dressed or change their clothes. One reason for this behavior may be the complexity of getting dressed, which involves many decisions. Making these decisions and trying to remember all of the steps involved may confuse or overwhelm the patient. A total of 77% of the caregivers interviewed reported that they had at some time been confronted by the problem of the patient having difficulty dressing him or herself. The mean stress rating for the problem of the patient having difficulty dressing him or herself was 4.52 (SD=2.92) with scores ranging from one to nine, and was the fourth most stressful memory and behavior problem experienced by caregivers of all the problems.

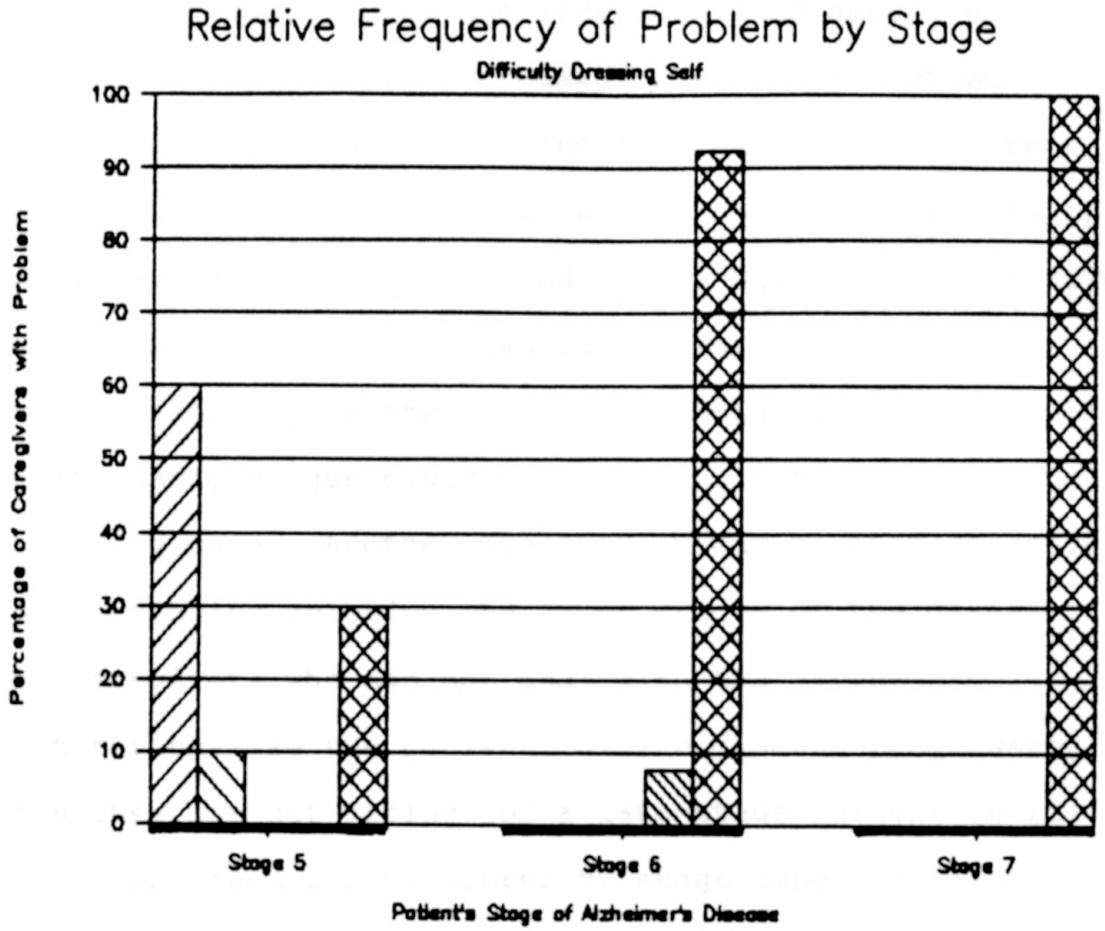
Frequency of Difficulty Dressing Self

The problem of the patient having difficulty dressing was ranked the seventh most frequent memory and behavior problems. According to Figure 26, this problem confronted 30% of the caregivers caring for persons in the fifth stage of the disease daily or more often. In stage six, almost 93% of the caregivers reported this frequency of the problem. In stage seven, all (100%) of the caregivers were confronted by this problem daily or more often.

Stress Associated with Difficulty Dressing Self

The Pearson Product Moment correlation between frequency and stress ($r=-0.34$, $p=.03$) indicated a

Figure 26



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

significant linear relationship between the two variables. These results suggest that as the frequency of the patient having difficultly dressing increased, the amount of stress caregivers experienced decreased. The Pearson Product Moment correlations between the frequency and the stress associated with the problems related to the activities of daily living (ADL's) often indicate a significant negative relationship between the two variables. The unpredictability of the problems associated with the ADL's in the early stages might be stressful rather than actually providing care. Another explanation may be that selection is functioning deleting the later stages of the disease. The caregivers who can not deal with the stress institutionalize the patient, as the disease progresses, and thus they are not caring for a late-stage patient in the home. The mean stress scores by stage experienced by caregivers remained fairly consistent throughout the last three stages of the disease (see Table 30). When the differences in stress by stage were examined using a Kruskal-Wallis test, the differences were not statistically significant (H^1=-1.31, k=3, $\underline{n}$=22).

Caregiver Control: Difficulty Dressing Self

For the problem of having difficulty dressing, there was a significant correlation between the amount of stress and control caregivers perceived (r=-0.40, $\underline{p}$=.01). These

Table 30

Amount of Stress Perceived by Caregivers Difficulty Dressing Self

Stage	M	SD	Range
5	5.50	2.08	3-8
6	4.46	2.96	1-9
7	4.60	3.65	1-9
All Stages	4.52	2.92	1-9

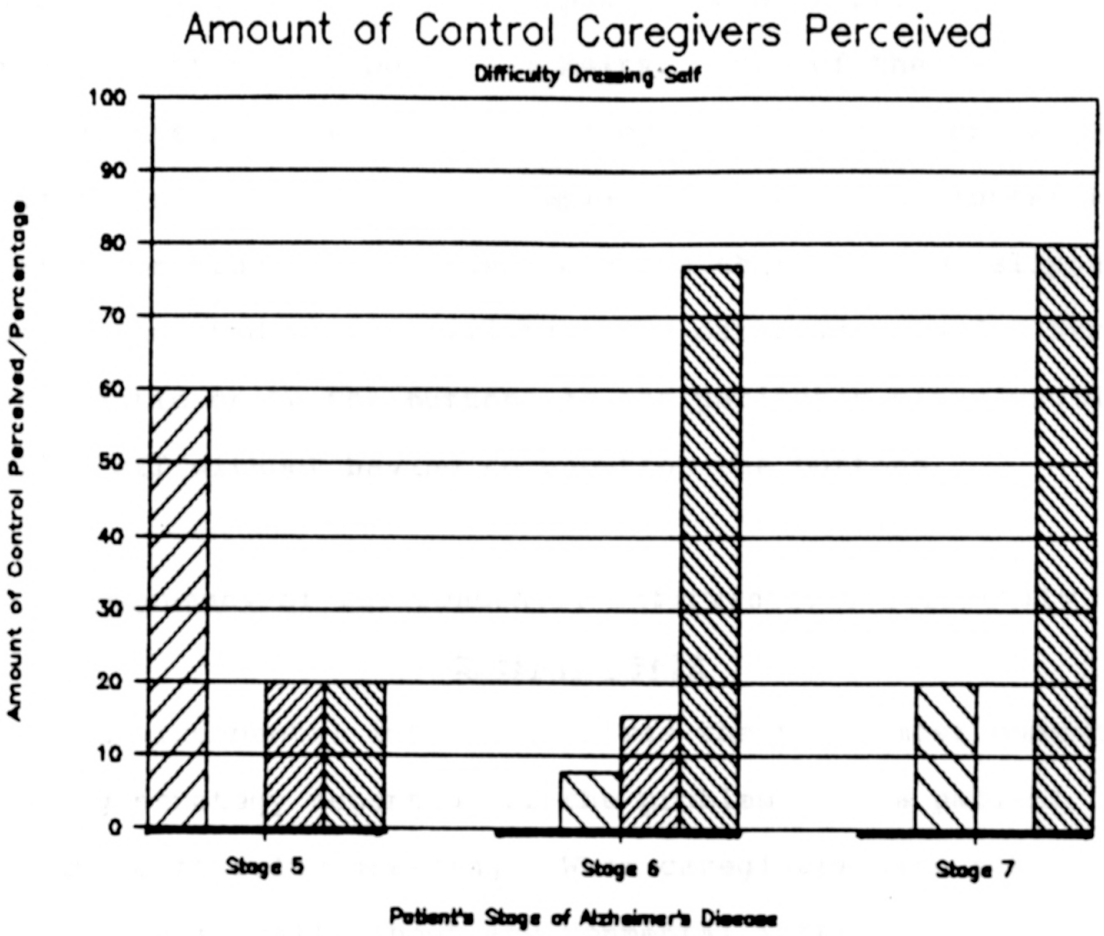
n=23

findings suggest that as the amount of stress associated with the problem of the patient having difficulty dressing increased, the amount of control the caregiver perceived they had in handling this problem declined. One explanation for the significant negative relationships frequently found between stress and control associated with the activities of daily living may be that acceptance is a moderator. Perhaps acceptance increases in the later stages with the amount of stress perceived dropping with an increase of acceptance. The amount of control caregivers perceived they had over handling this problem also varied. According to Figure 27, in stage five, only 20% of the caregivers felt they had no control over handling this problem. This percentage rose to approximately 77% in stage six. In stage seven, 80% of the caregivers felt they had no control over handling this problem. However, when the differences in control by stage were examined using a Kruskal-Wallis test, the results were not statistically significant (H^1=2.13, k=3, $\underline{n}$=22).

Frequency of Coping Strategies Used: Difficulty Dressing Self

The total number of coping strategies reported for handling the problem of the person having difficulty dressing him or herself was 41. Direct action and acceptance were the two most common ways of coping with this problem, and made up almost 78% of the coping strategies

Figure 27



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

used (see Table 31). As the disease progressed, caregivers reported that they tried to accept that it would become more difficult for the patient to put clothes on properly and to manage buttons, zippers, and belts. Some of the caregivers bought the patient shoes that they could slip on or velcro instead of tie. They also replaced buttons and zippers with velcro or bought the patient clothes that could be slipped on or that had elastic waists. One caregiver sewed a strip of elastic on to the buttons so the patient's pants could slide off without having to unbutton the buttons.

Frequency of Environmental Intervention: Difficulty Dressing Self

Environmental intervention was the third most common coping strategy reported for the problem of the patient having difficulty dressing. When caregivers were asked to think specifically about environmental interventions they reported a total of 12 environmental interventions for this problem, with 81% reported to have been successful. Some of the environmental interventions caregivers found helpful in the early stages of the disease included choosing the patient's clothes and laying the them out in the order that they were to be put on. Some caregivers felt it helped to leave the patient's clothing in the same place they had always put it. Other caregivers found that cleaning out the patients closet helped because they eliminated the number of

Table 31

Rank Order of Coping Strategies Used
Difficulty Dressing Self

Coping Strategy	Percentage Used	
Direct Action	41%	(n=17)
Acceptance	37%	(n=15)
Environmental Intervention	7%	(n=3)
Situation Redefinition	5%	(n=2)
Social Support	5%	(n=2)
Catharsis	2%	(n=1)
Religion	2%	(n=1)
Distraction	0%	(n=0)
Relaxation	0%	(n=0)

n=23

choices for the patient. They also consolidated similar items in one location. For example, they put all the shirts on one side of the closet and all the pants on the other side. To help the patient dress for the appropriate season, caregivers often put away out-of-season clothes. These interventions are described in Pynoos and his associate's (1988) environmental management strategy of simplifying tasks and the environment. However, when the differences by stage of diseases in environmental management were examined for the problem of dressing, the results of the Kruskal-Wallis test were not statistically significant (H^1=3.42, k=3, $\underline{n}$=22).

Difficulty Feeding Self

Nutritional problems, such as malnutrition and dehydration, can aggravate mental problems. There are many problems which can arise during mealtime that can make maintaining the patient's nutritional needs difficult. For example, the patient may have difficulty drinking, chewing and swallowing making it frustrating to eat. A total of 60% of the caregivers interviewed had at some time been confronted by the problem of the patient having difficulty feeding him or herself. The mean stress score for this problem was 3.50 ($\underline{SD}$=2.09) with scores ranging from 1 to 8.

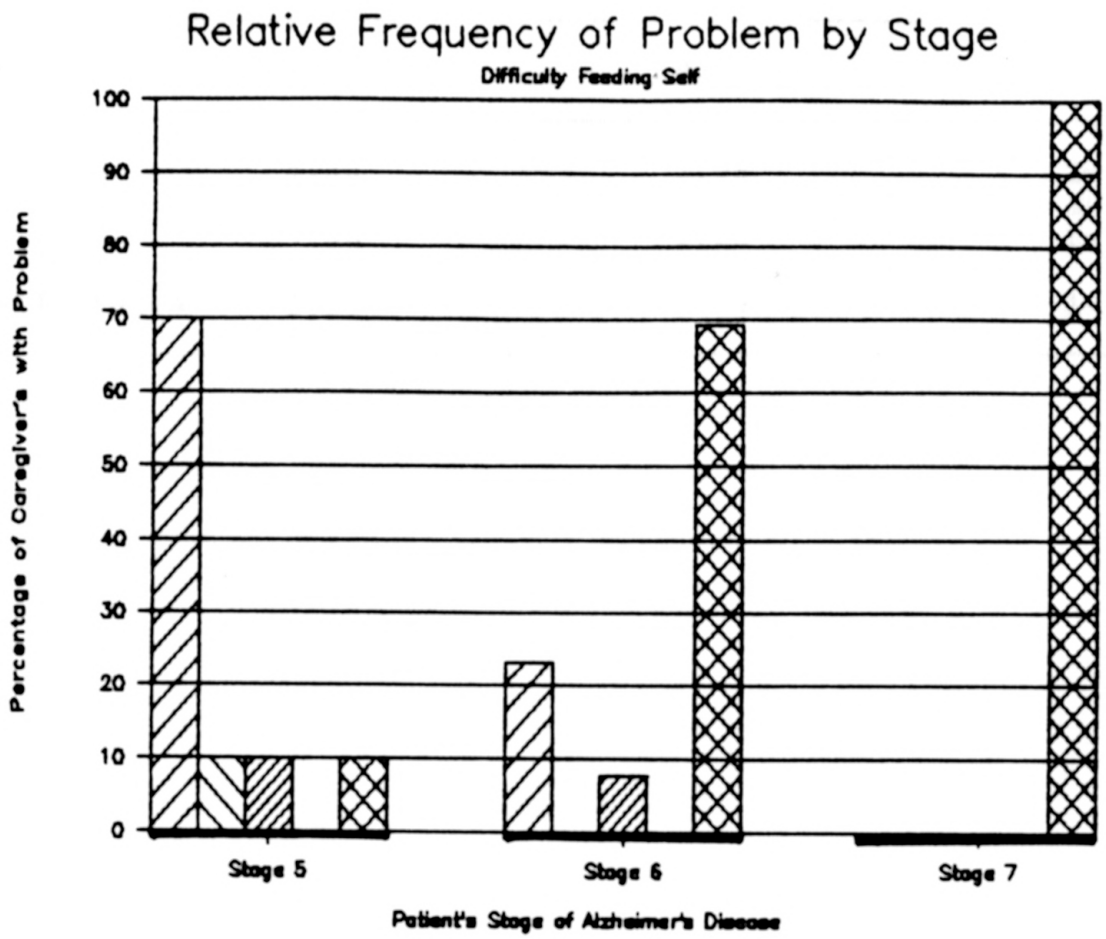
Frequency of Difficulty Feeding Self

The problem of the patient's difficulty feeding him or herself was one of the least frequent problems experienced by caregivers of all of the memory and behavior problems included in this study. The frequency of this problem increased as the stages of the disease progressed, as shown in Figure 28. The patients began to have difficulty feeding themselves when they began to develop problems with their motor skills and coordination. In stage five, most patients only had difficulty feeding themselves occasionally. However, in stage six, almost 70% of the caregivers reported that this problem occurred daily or more often. In stage seven, all (100%) of the caregivers were confronted by this problem daily or more often.

Stress Associated with Difficulty Feeding Self

The correlation between the frequency of the patient's difficultly feeding him or herself and the stress associated with this problem by the caregivers ($r=-0.36$, $p=.02$) indicated a significant negative linear relationship between the two variables: greater frequency of the problem was associated with less stress. This problem was one of the least stressful problems experienced by caregivers of all the problems studied, and the mean stress scores experienced by caregivers fluctuated somewhat throughout the last three stages of the disease (see Table 32). When the differences

Figure 28



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Table 32

Amount of Stress Perceived by Caregivers Difficulty Feeding Self

Stage	M	SD	Range
5	4.33	2.08	2-6
6	3.10	2.13	1-8
7	3.80	2.28	1-7
All Stages	3.50	2.09	1-8

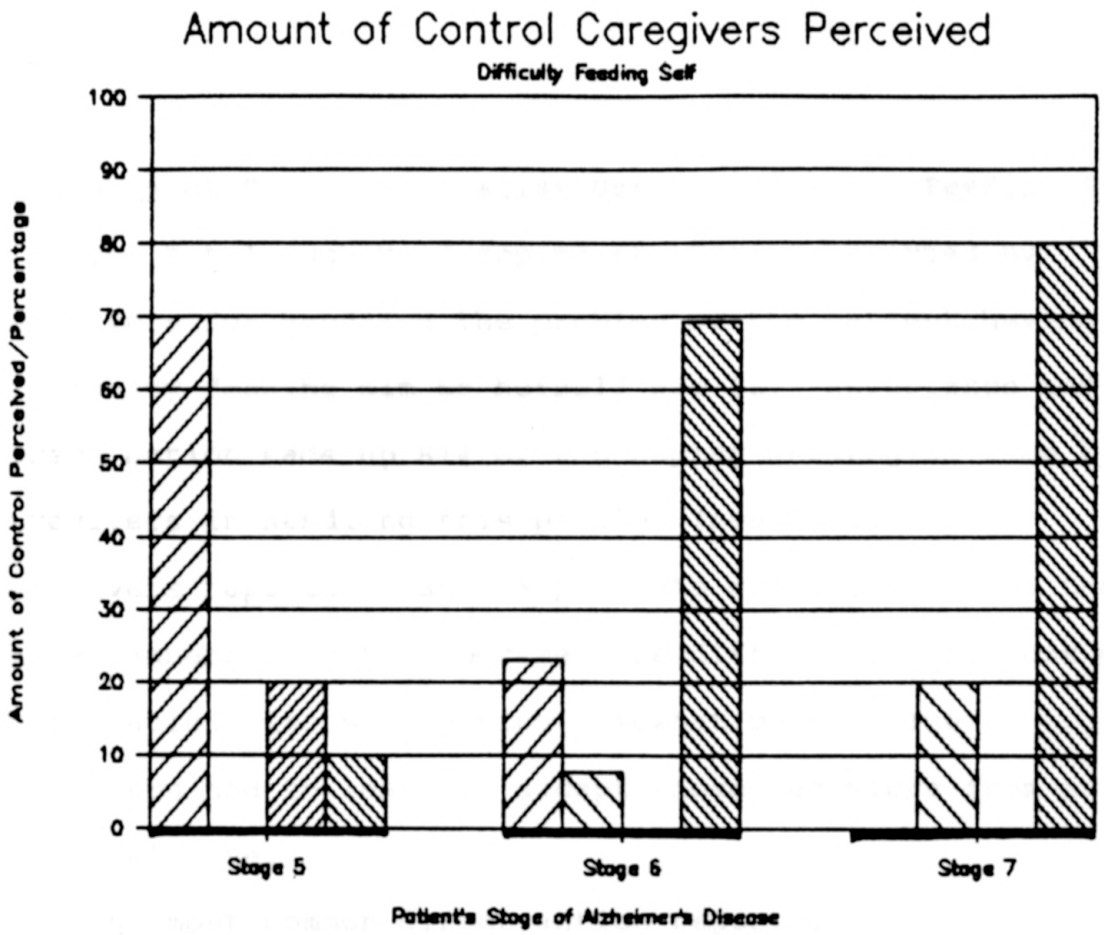
n=18

in stress by stage were examined using a Kruskal-Wallis test, the differences were not statistically significant (H^1=2.60, k=3, $\underline{n}$=18). Some caregivers may have perceived higher levels of stress when this problem occurred sporadically, perhaps making it more difficult for the caregiver to learn what situations and foods that may cause difficulties.

Caregiver Control: Difficulty Feeding Self

The Pearson Product Moment correlation coefficient between stress and control (r=-0.42, $\underline{p}$=.01) indicated a significant negative linear relationship between the two variables. For the problem of the patient having difficulty feeding him or herself, greater perceptions of stress were associated with less perceived control. Acceptance may explain the low stress. Most of the caregivers perceived that they had no control over handling this problem. According to Figure 29, in stage five, 20% of the caregivers reported that they felt they had no control over handling this problem. In stage six, this percent rose to almost 70%. By stage seven, 80% of the caregivers felt that they had no control over handling this problem. However, when the differences in control by stage were examined using a Kruskal-Wallis test, the differences were not statistically significant (H^1=2.60, k=3, $\underline{n}$=18). The perceptions of many caregivers that they have no control over this problem in

Figure 29



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

the late stages of the disease may be attributed to the ability of most patients to manage with some assistance to feed themselves throughout most of the course of the disease.

Frequency of Coping Strategies Used: Difficulty Feeding Self

The total number of coping strategies reported by caregivers for handling the problem of the patient having difficulty feeding him or herself was 31. Acceptance and direct action made up 81% of the coping strategies used by caregivers in handling this problem (see Table 33). Caregivers reported that the patients gradually forgot their table manners as eating became more difficult. The loss of coordination also made eating somewhat messy. The caregivers had to learn to accept those behaviors from an adult relative.

The most common direct action reported by the caregivers was to help or assist the patient in eating, and to prepare meals that the patient could manage easily. Some caregivers only had to cut the patient's meat while others had to spoon feed the patient.

Frequency of Environmental Intervention: Difficulty Feeding Self

Environmental intervention was tied with catharsis as the third most common coping strategy employed for handling

Table 33

Rank Order of Coping Strategies Used Difficulty Feeding Self

Coping Strategy	Percentage Used
Acceptance	45% (n=14)
Direct Action	35% (n=11)
Environmental Intervention	6% (n=2)
Catharsis	6% (n=2)
Situation Redefinition	3% (n=1)
Social Support	3% (n=1)
Distraction	0% (n=0)
Relaxation	0% (n=0)
Religion	0% (n=0)

n=18

this problem. A Kruskal-Wallis test was employed to examine the differences in environmental management used by caregivers caring for patients in the last three stages of the disease. The results were not statistically significant (H^1=1.21, k=3, $\underline{n}$=18).

Caregivers reported many different environmental interventions when they were asked to describe in detail their use of environmental interventions for this problem. When the patient first began to have difficulty with coordination, many caregivers found that the patient was able to manage a salad fork better than a dinner fork and that plates with high rims were helpful. Later in the disease most caregivers tried to reduce the number of selections they gave the patient by using spoons and bowls for everything and limiting the number of foods they served at a meal. As the disease progressed, some caregiver served food that the patient could manage easily or eat with their fingers. Eventually, most patients had to be spoon fed or drink their meal through a straw. Some caregivers hired someone to come in and feed the patient. A total of 30 environmental interventions were employed by caregivers, with 97% of them reported to have been successful.

Difficulty Toileting Self

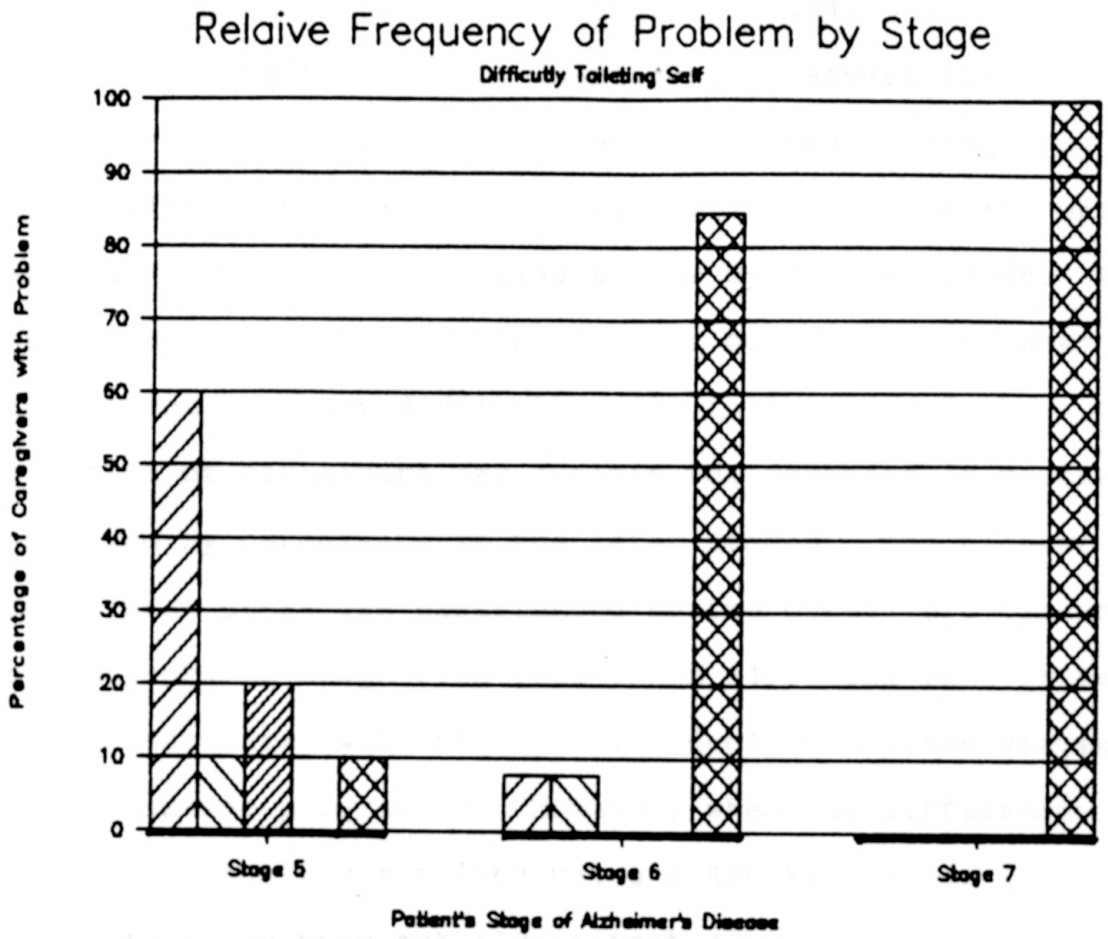
Patients suffering from Alzheimer's disease loose track of the immediate past, and therefore may forget how long it

has been since they last used the toilet. The patient with impaired memory may also forget the physiological signals that prompt using the toilet or may have difficulty remembering where the bathroom is located or what to do once in the bathroom. As a result "accidents" frequently occur. A total of 70% of the caregivers interviewed reported that at some time they had been confronted by the problem of the patient having difficulty toileting him or herself. The mean stress score was 4.00 (SD=3.02) with scores ranging from 1 to 10.

Frequency of Difficulty Toileting Self

The frequency of the problem of the patient having difficulty toileting was tied with the problems of engaging in behavior dangerous to him or herself and difficulty seeing or hearing things, and was ranked ninth of all the problems (see Table 8). This problem occurred throughout the last three stages of the disease, but increased in frequency as the stages of the disease progressed. According to Figure 30, most of the caregivers in stage five reported that this problem happened only one to two times a week. However, in stage six approximately 85% of the caregivers reported that this problem occurred daily or more often. In stage seven, all (100%) of the caregivers were confronted by this problem daily or more often.

Figure 30



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Stress Associated with Difficulty Toileting Self

The Pearson Product Moment correlation coefficient between frequency and stress ($r=-0.32$, $p=.04$) indicated a significant negative linear relationship between the two variables. These findings suggest that greater frequency of the problem of the patient having difficulty toileting was associated with less perceived stress by the caregiver. The unpredictability early in the disease of not knowing when the patient may have difficulty with toileting and the selection of caregivers may explain the decrease in stress perceived by caregivers in the later stages. The highest mean stress score was experienced by the caregivers caring for patients in stage five (see Table 34). The mean stress scores associated with this problem declined as the stages of the disease progressed. However, when the differences in stress by stage was examined using a Kruskal-Wallis test, the differences were not significant ($H^1=3.17$, $k=3$, $n=21$).

Caregiver Control: Difficulty Toileting Self

The correlation between perceived stress and control for the problem of the patient having difficulty toileting indicated a significant negative linear relationship between the two variables ($r=-0.47$, $p=.005$). These finding suggest that greater perceptions of stress were associated with less perceived control. Most caregivers perceived that they had no control over handling this problem. As the disease

Table 34

Amount of Stress Perceived by Caregivers Difficulty Toileting Self

Stage	M	SD	Range
5	5.75	1.71	4-8
6	4.08	3.53	1-10
7	2.40	1.67	1-5
All Stages	4.14	3.01	1-10

n=21

progressed, the percentage of caregivers who perceived that they had no control increased (see Figure 31). However, the percentage of caregivers who perceived they had extensive control also increased as the stages of the disease progressed.

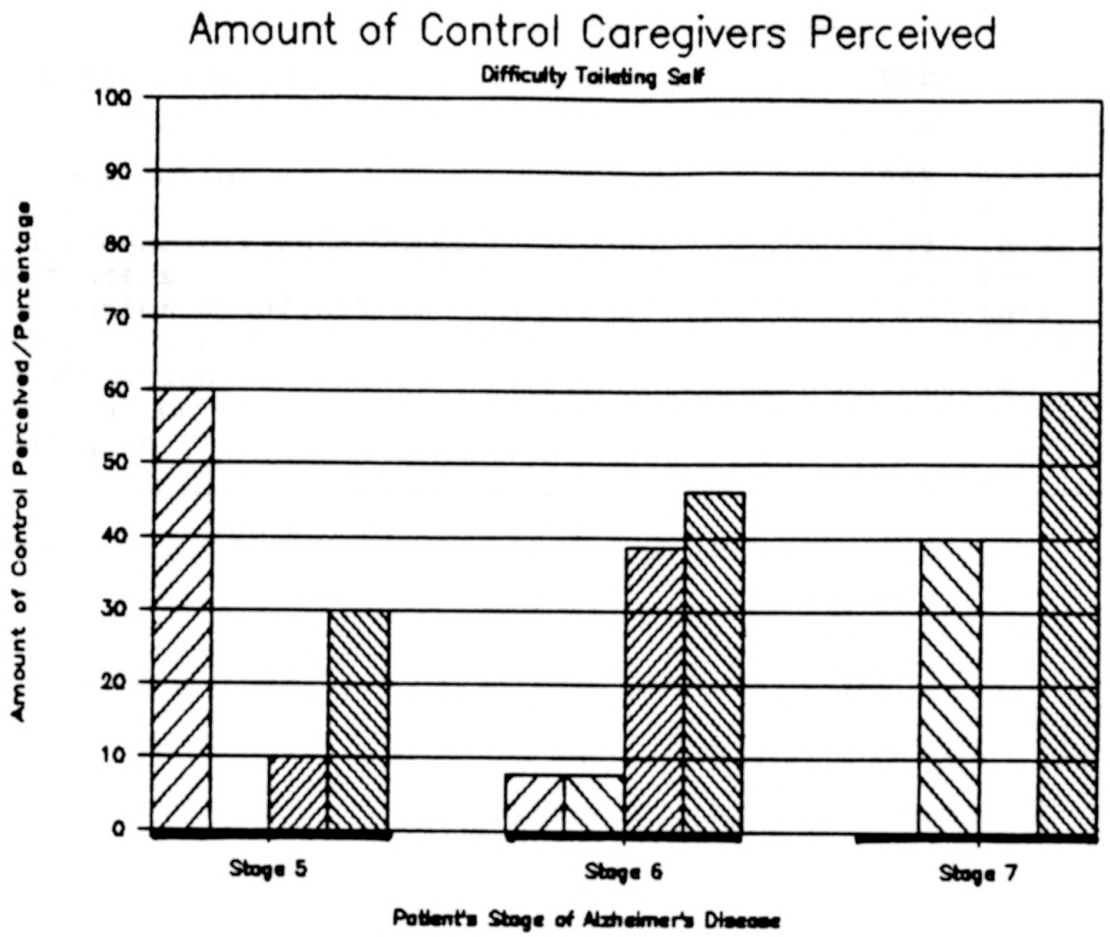
Frequency of Coping Strategies Used: Difficulty Toileting Self

The total number of coping strategies reported for handling the problem of the patient having difficulty toileting was 44. As shown in Table 35, direct action and acceptance were used approximately 64% of the time and were the two most frequent coping strategies used by caregivers. The most common forms of direct action used by caregivers were aimed at trying to prevent accidents from occurring. The types of direct action taken by caregivers included: reminding the patient to use the bathroom, taking the patient to the toilet every two to three hours, limiting the amount of fluids the patient had before bedtime, directing the patient's attention to what was to be done while in the bathroom, and staying near the patient until he or she was finished.

Frequency of Environmental Interventions: Difficulty Toileting Self

Environmental intervention was the third most common

Figure 31



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

Table 35

Rank Order of Coping Strategies Used
Difficulty Toileting Self

Coping Strategy	Percentage Used
Direct Action	36% (n=16)
Acceptance	27% (n=12)
Environmental Intervention	14% (n=6)
Catharsis	9% (n=4)
Situation Redefinition	7% (n=3)
Social Support	7% (n=3)
Distraction	0% (n=0)
Relaxation	0% (n=0)
Religion	0% (n=0)

n=21

coping strategy employed while handling this problem. A Kruskal-Wallis test was conducted to examine the differences in environmental management used by caregivers caring for patients in the last three stages of the disease. The results were not statistically significant (H^1=2.03, k=3, $\underline{n}$=21).

Some of the most common environmental interventions reported by caregivers when asked to describe in detail their use of environmental intervention for this problem included the following: covering chairs and sofas to prevent them from being ruined, installing grab bars and raising the height of the toilet seat to make the use of the toilet safer, and leaving the lights on and the door open so that the patient could locate the bathroom easier.

Most patients and caregivers were modest about toileting because it is regarded as a personal behavior. However, one caregiver found that it helped the patient if she closed the blinds or had a person of the same sex take the patient to the bathroom. For male patients, some caregivers found it helped to have them stand as close as possible to the toilet, to place towels on the floor beside the stool to aid in cleaning up, or to sit straddling the stool facing the wall.

This problem seemed to become more frequent at night. One explanation may be the patient's difficulty reaching the bathroom quickly. When this was the problem, some

caregivers found that putting a port-a-potty or bed pan near the patient's bed was helpful. Caregivers reported that at other times, the patient was not aware of the need to used the toilet at night, and they found it necessary to put a plastic sheet or waterproof pad on the bed. A total of 28 environmental interventions were employed by caregivers, with 86% of them were reported to have been successful.

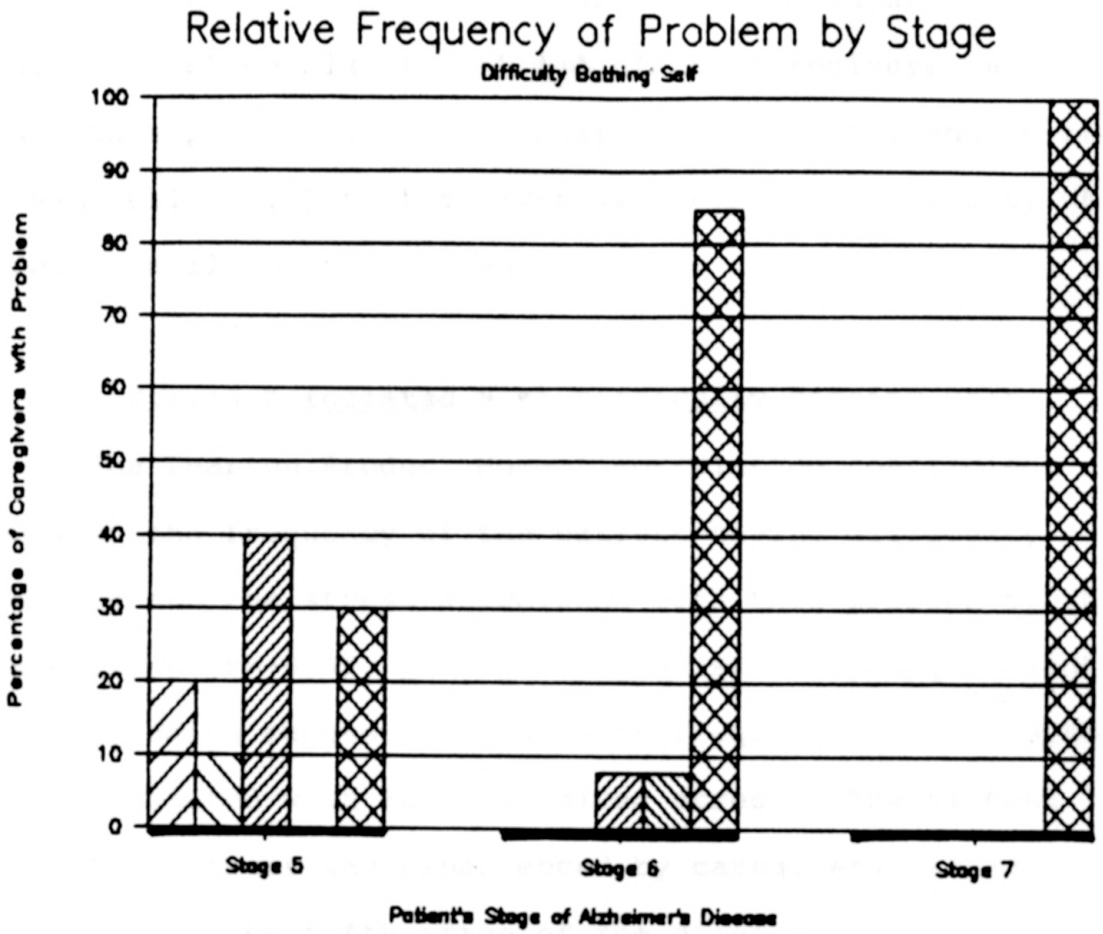
Difficulty Bathing Self

Bathing is a complicated task with many different steps and decisions. Thus it can easily become overwhelming for a person with memory impairment. Some patients with Alzheimer's disease will refuse to bathe, while others do not remember when they had their last bath and will refuse to take another one because they think it is not yet time for a bath. A total of 90% of the caregivers interviewed were at some time confronted by the problem of the patient having difficulty bathing. The mean stress ratings for this problem was 4.56 (SD=3.27) with scores ranging from 1 to 10, making it one of the most stressful memory and behavior problems experienced by caregivers (see Table 9).

Frequency of Difficulty Bathing Self

The problem of the Alzheimer's disease patient having difficulty bathing was the fifth most frequent problems experienced by caregivers. As shown in Figure 32, the

Figure 32



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

frequency of this problem increased as the stages of the disease progressed. In stage five, most of the caregivers reported that this problem occurred two to three times a week. In stage six, almost 85% of the caregivers reported that this problem occurred daily or more often, and in stage seven, all (100%) of the caregivers were confronted by this problem daily or more often.

Stress Associated with Difficulty Bathing Self

The Pearson Product Moment correlation coefficient between the frequency of the patient having difficulty bathing and the stress associated with this problem by the caregivers ($r=-0.39$, $p=.02$) was statistically significant. These finding suggest that greater frequency of this problem was associated with less perceived stress. The highest amount of stress was experienced by caregivers caring for patients in the fifth stage of the disease. The amount of stress reported declined slightly for caregivers of patients in stage six and dropped again in stage seven (see Table 36). When the differences between stress by stage were examined using a Kruskal-Wallis test, the differences were statistically significant ($H^1=11.43$, $k=3$, $n=26$, $p>.05$).

The high level of stress experienced by caregivers was often associated with the many problems that arose when trying to get an Alzheimer's disease patient to take a bath. Bathing is a very private activity, therefore many patients

Table 36

Amount of Stress Perceived by Caregivers Difficulty Bathing Self

Stage	M	SD	Range
5	4.88	2.53	2-10
6	4.77	3.96	1-10
7	2.80	2.05	1-5
All Stages	4.56	3.27	1-10

n=27

are modest and may resent or refuse help. In addition to the feelings of confusion and embarrassment associated with being bathed by a caregiver, many patients also developed a fear of the water. According to caregivers, these factors often precipitated catastrophic reactions.

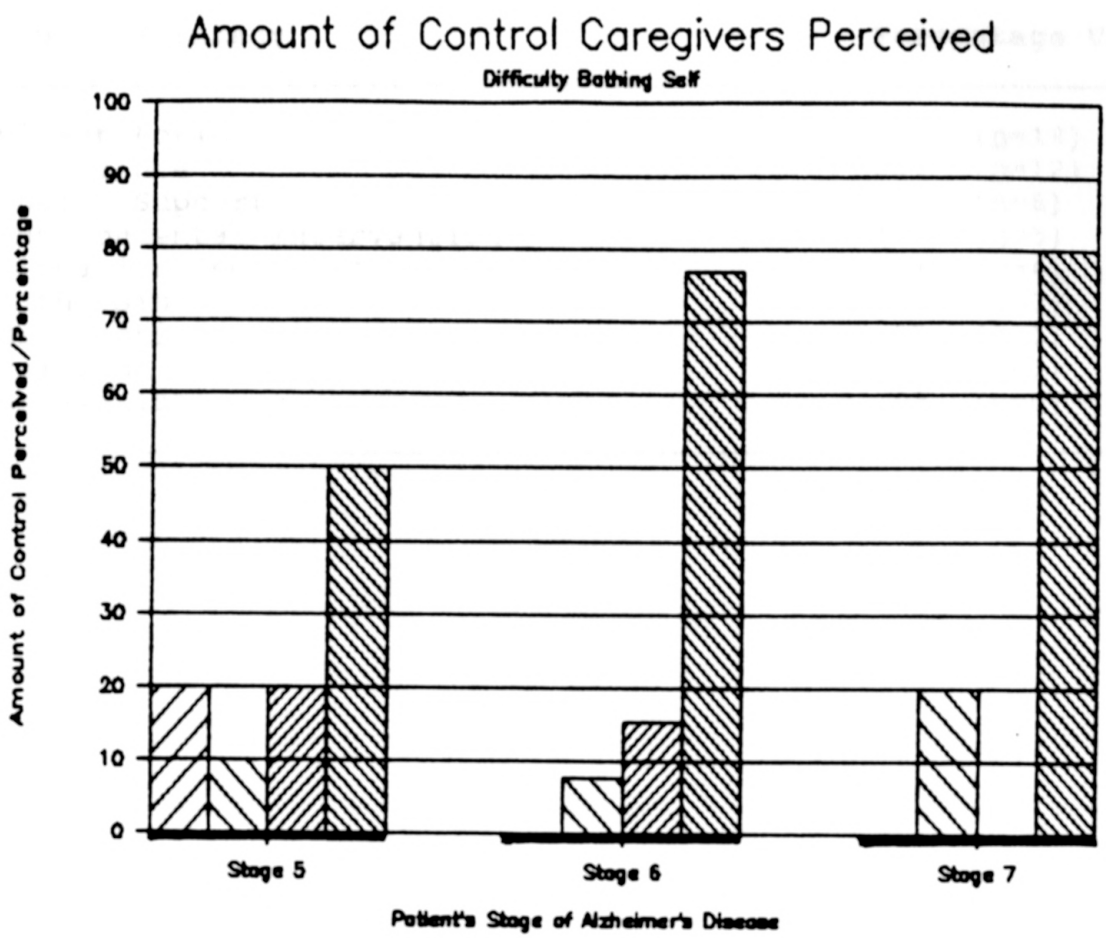
Caregiver Control: Difficulty Bathing Self

The results of the Pearson Product Moment correlation coefficient indicated a significant negative linear relationship between the variables of stress and control associated with this problem ($r=-0.46$, $p=.006$). The findings suggest that higher perceived stress was associated with less perceived control. Most caregivers perceived they had no control over handling the problem of the person with Alzheimer's disease having difficultly bathing. As shown in Figure 33, the perceptions of no control increased from 50% to 80% from stage five to stage seven. However, when a Kruskal-Wallis test was used to examine the differences in control by stages of the disease, the results were not statistically significant ($H^1=-0.23$, $k=3$, $n=26$).

Frequency of Coping Strategies Used: Difficulty Bathing Self

The total number of coping strategies reported for handling the problem of the patient having difficulty bathing was 50. As shown in Table 37, direct action and acceptance were used approximately 60% of the time, and were

Figure 33



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

Table 37

Rank Order of Coping Strategies Used
Difficulty Bathing Self

Coping Strategy	Percentage Used
Direct Action	36% (n=18)
Acceptance	24% (n=12)
Social Support	12% (n=6)
Environmental Intervention	10% (n=5)
Situation Redefinition	8% (n=4)
Catharsis	6% (n=3)
Distraction	2% (n=1)
Religion	2% (n=1)
Relaxation	0% (n=0)

n=27

the two most common ways of handling this problem. The types of direct action taken by caregivers ranged from running the bath water or helping the patient in and out of the tub to getting in the shower and showering with the patient. Some caregivers reported that they hired someone to come in and bathe the patient. One caregiver had her grown son come in to bathe his father because the patient was too big and strong for the caregiver to manage by herself. Other caregivers simply decided that the patient really didn't need a bath everyday.

Social support was used approximately 12% of the time, and was the third most common coping strategy used to handle this problem. Some caregivers talked with relatives or close friends, others attended support group meetings, while others brought in home care workers or others to help them bathe the patient.

Frequency of Environmental Interventions: Difficulty Bathing Self

When this problem occurred, environmental intervention was the fourth most common coping strategy employed. There were no significant differences in the use of environmental interventions by caregivers caring for patients in the last three stages of the disease, as documented by a Kruskal-Wallis test ($H^{l}=3.72$, $k=3$, $\underline{n}=26$).

The third largest number of environmental interventions

were attempted for the problem of the patient having difficulty bathing. When caregivers were asked to think specifically about environmental interventions for this problem they reported a total of 40 environmental interventions, with 88% of them reported to have been successful. Some of the most common environmental interventions used by caregivers included: putting rubber mats or slip resistent stickers on the bottom of the tub, installing secure grab bars and hand held shower heads, and putting a small stool in the tub so that the patient could get in and out of the tub more easily. The environmental management strategy of introducing environmental modifications (Pynoos and his associates, 1988) includes these types of environmental interventions.

Difficulty Grooming Self

One problem that seems to occur early in the disease is the patient's loss of interest in keeping him or herself well groomed. Even people who have been particular about their appearance all their lives seem to have difficulty maintaining their hair, nails, face, clothing and overall appearance. A total of 93% of the caregivers interviewed were at some time confronted by the problem of the patient having difficulty grooming him or herself. The mean stress score for this problem was 3.25 (SD=2.89) with scores ranging from 1 to 10.

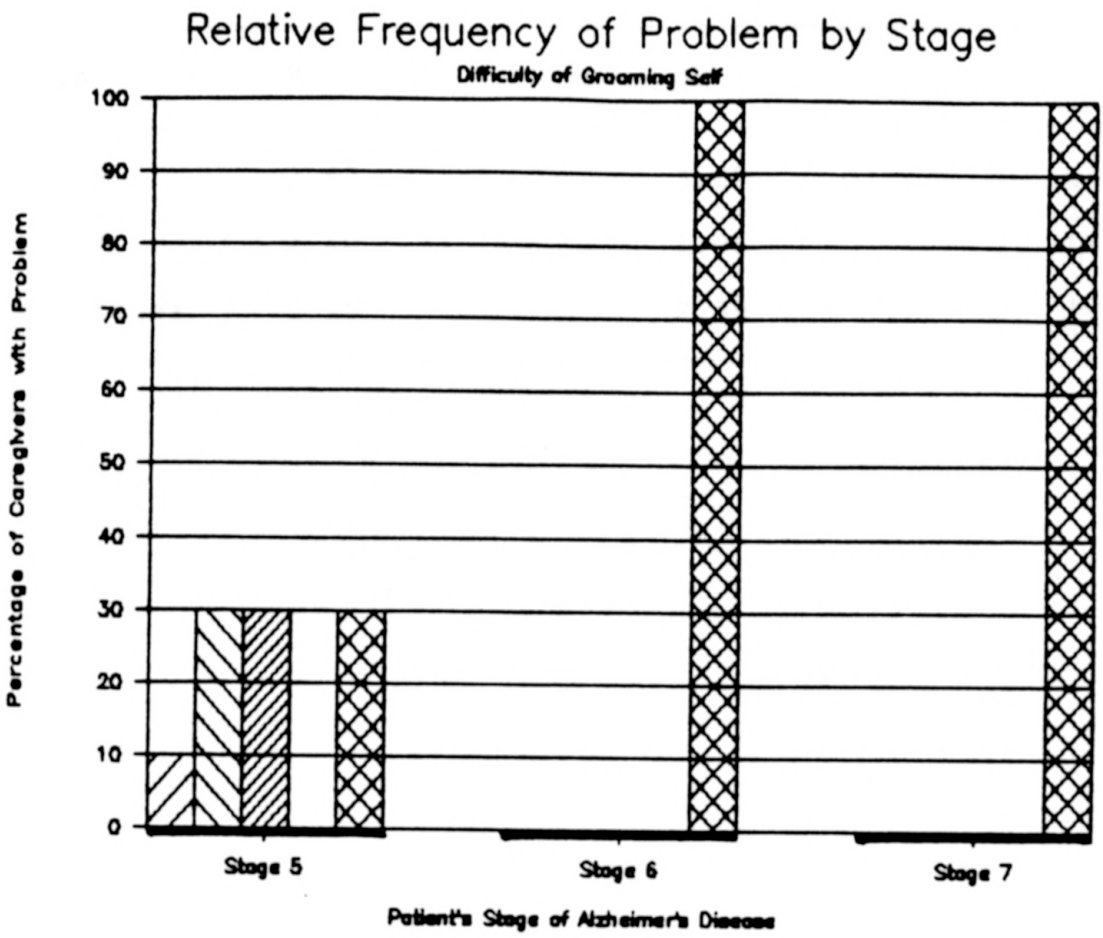
Frequency of Difficulty Grooming Self

This problem was one of the most frequent memory and behavior problem experienced by caregivers, and the amount of difficulty the patient had in grooming increased as he or she became more impaired. The frequency of this problem increased as the stages of the disease progressed. As shown in Figure 34, 90% of the caregivers caring for patients in the fifth stage were at some time confronted by the this problem while 30% reported that the problem occurred daily or more often. In stages six and seven, all (100%) of the caregivers reported this problem occurred daily or more often. The correlation between the frequency of the problem of the patient having difficulty grooming and the stress associated with this problem by the caregivers was statistically significant ($r=-0.33$, $p=.04$): greater frequency of the problem was associated with lower perceived stress.

Stress Associated with Difficulty Grooming Self

The problem of the patient with Alzheimer's disease having difficulty grooming was one of the least stressful memory and behavior problems experienced by caregivers. According to Table 38, the highest amount of stress was experienced by caregivers caring for patients in the fifth stage of Alzheimer's disease. Caregivers caring for patients in stages five, six, and seven did not experience

Figure 34



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Table 38

Amount of Stress Perceived by Caregivers Difficulty Grooming Self

Stage	M	SD	Range
5	3.67	3.67	1-10
6	3.31	2.84	1-10
7	2.40	1.95	1-5
All Stages	3.25	2.89	1-10

n=28

significant differences in the amount of stress (H^1=1.94, k=3, n=27). High stress scores often were reported by caregivers of patients who refused to take care of their own personal hygiene or refused help from others.

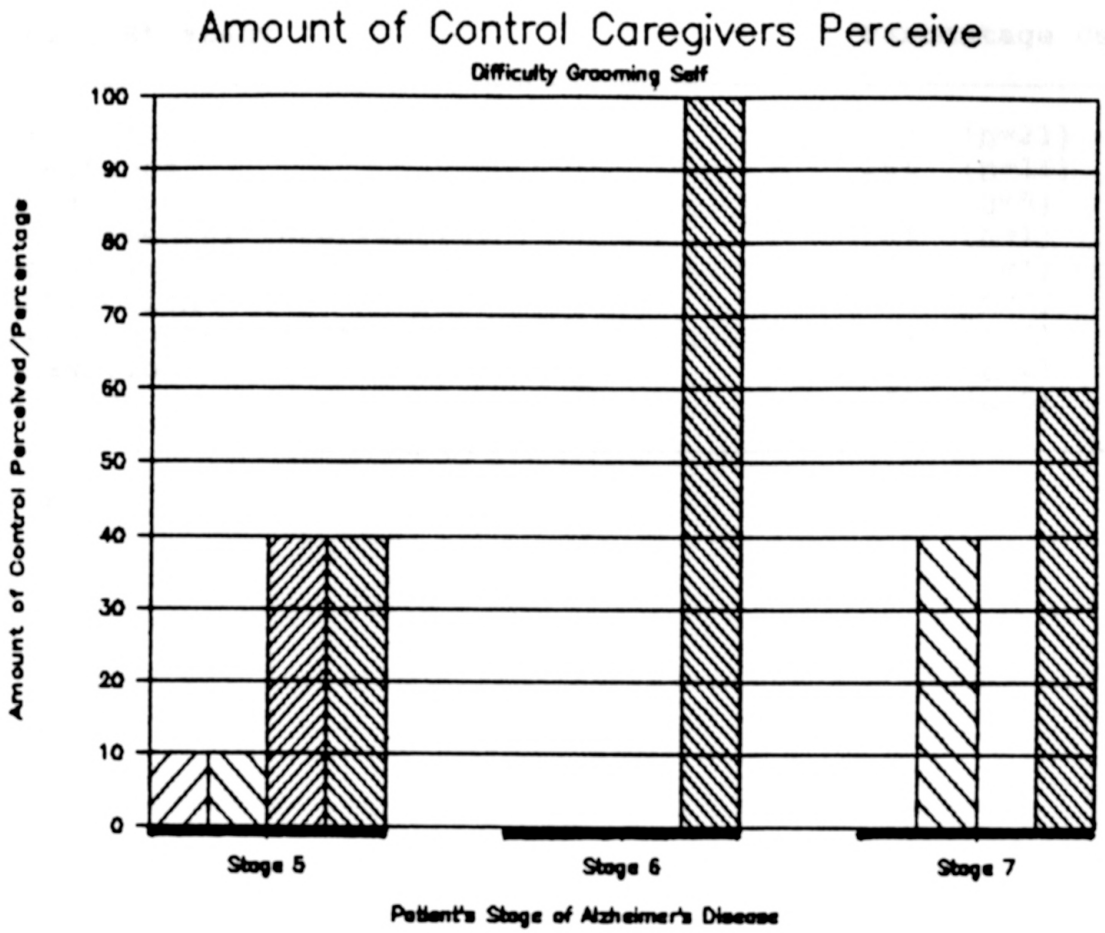
Caregiver Control: Difficulty Grooming Self

The Pearson Product Moment correlation coefficient between stress and control (r=-0.37, p=.02) for the problem of grooming indicated a significant negative linear relationship between the two variables: higher perceived stress was associated with less perceived control. The majority of caregivers perceived that they had no control over handling this problem. The perception of no control was highest in stage six (see Figure 35), where all (100%) of the caregivers reported they perceived no control. When the differences in control by stage were examined using a Kruskal-Wallis test, the results were statistically significant (H^1=9.59, k=3, n=27, p>.05).

Frequency of Coping Strategies Used: Difficulty Grooming Self

The total number of coping strategies reported for handling the problem of difficulty grooming was 44. As shown in Table 39, direct action and acceptance were used approximately 84% of the time and were the two most frequent coping strategies. Social support was used approximately

Figure 35



▨ = Problem doesn't apply

▧ = Quite a lot/complete control

▨ = Some control

▨ = No control

Table 39

Rank Order of Coping Strategies Used
Difficulty Grooming Self

Coping Strategy	Percentage Used
Direct Action	48% (n=21)
Acceptance	36% (n=16)
Social support	11% (n=5)
Environmental Intervention	2% (n=1)
Catharsis	2% (n=1)
Distraction	0% (n=0)
Situation Redefinition	0% (n=0)
Relaxation	0% (n=0)
Religion	0% (n=0)

n=28

11% of the time and was the third most frequent coping strategies used in handling this problem.

The most common form of direct action taken by caregivers was to assist patients in those tasks. Other caregivers found is easier to hire someone to come in and help. One caregiver reported that the patient viewed the home care worker as a social friend who had come for a visit and washing her hair became an enjoyable activity. Other caregivers took the patient to an adult day care center a few times a week. Some centers bathed the patients, washed their hair, and helped take care of the patients' nails.

Frequency of Environmental Interventions: Difficulty Grooming Self

When caregivers confronted with the problem of the patient having difficulty grooming, environmental intervention was tied with catharsis for the fourth most common coping strategy employed. For this problem there was not a significant difference in environmental management used by caregivers caring for patients in the last three stages of the disease (H^1=1.93, k=3, $\underline{n}$=27).

When caregivers were questioned in detail about environmental interventions the most common environmental intervention reported was to remove grooming supplies from the patient's bedroom and bath to prevent their inappropriate use, such as drinking the shampoo. Caregivers

also reported that they replaced the patient's razor blades with an electric razor. These types of environmental interventions fit into Pynoos and his associates' (1988) environmental management strategies of removing and modifying objects and simplifying tasks and the environment. Of all of the problems, the smallest number of environmental interventions were reported for the problem of the patient having difficulty grooming. A total of two environmental interventions were reported, with both (100%) reported to have been successful.

Difficulty Moving Around

Most people with Alzheimer's disease gradually develop a shuffling gate as their walking becomes unsteady. This may cause the patient to be clumsy and trip or run into things frequently. During the later stages of the disease, the patient often becomes stiff and rigid, and eventually becomes completely bedridden. Approximately 47% of the caregivers interviewed were at some time confronted by the problem of the patient having difficulty moving around. The mean stress score for this problem was 3.00 (SD=2.42) with scores ranging from 1 to 8.

Frequency of Difficulty Moving Around

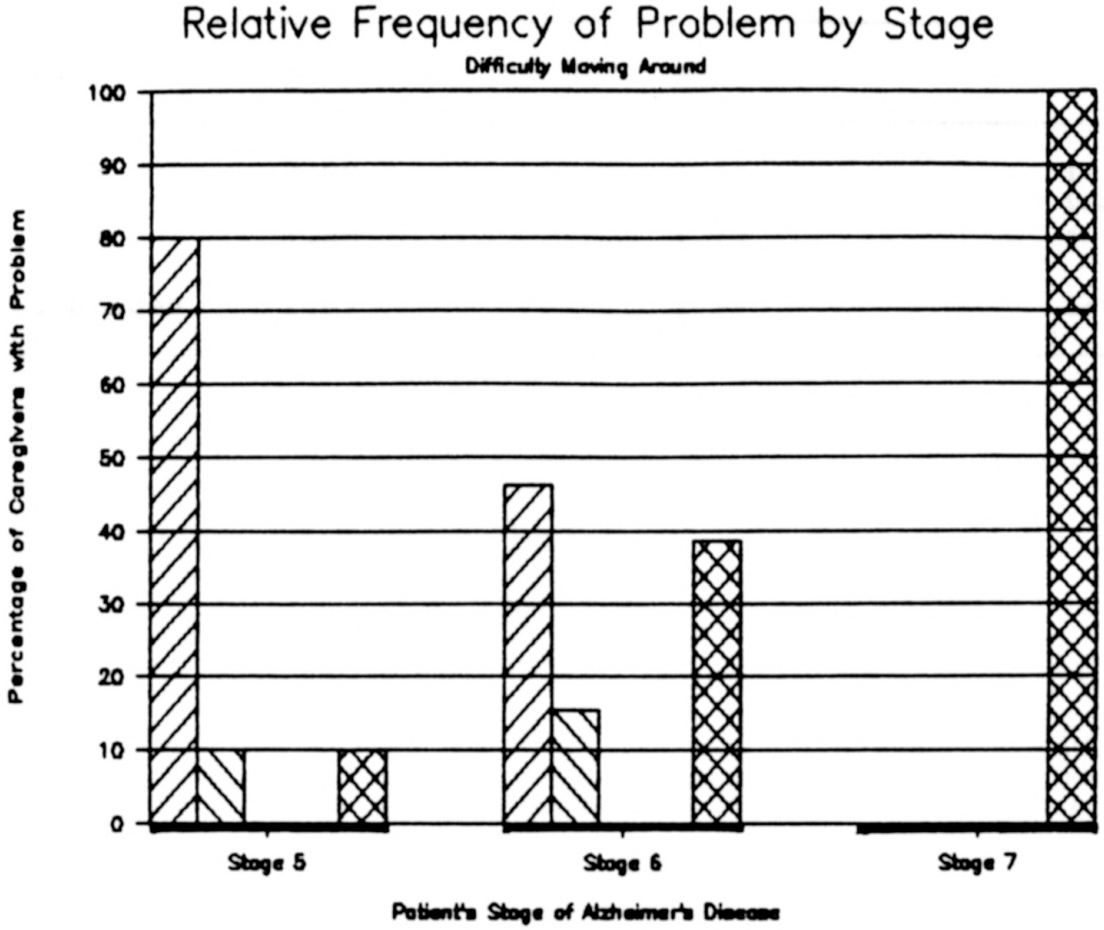
This problem was the second least frequent memory and behavior problem experienced by caregivers. According to

Figure 36, the frequency of this problem increased dramatically in the last stage of the disease. In stage five, 10% of the caregivers reported that this problem occurred daily or more often. The percentage rose to approximately 39% in stage six, and in stage seven all (100%) of the caregivers reported that this problem occurred daily or more often. The Pearson Product Moment correlation coefficient between frequency and stress ($r=-0.58$, $p=.000$) indicated a significant linear relationship between the two variables. These results suggest that as the frequency of this problem increased the amount of stress perceived by caregivers decreased.

Stress Associated with Difficulty Moving Around

The problem of the patient having difficulty moving around was the second least stressful problem experienced by the caregivers. The amount of stress experienced by the caregivers for this problem fluctuated throughout the last three stages of the disease (see Table 40). The results of this analysis were statistically significant ($H^1=22.52$, $k=3$, $n=13$, $p>.05$). The highest mean stress scores were experienced by caregivers of patients in the sixth stage. The high stress scores often were associated with patients who tripped and fell frequently. A Kruskal-Wallis test was conducted to examine the differences in mean stress scores by stage of the disease.

Figure 36



= never occurred

= has occurred, but not in the past week

= has occurred 1 or 2 times in the past week

= has occurred 3 to 6 times in the past week

= occurs daily or more often

Table 40

Amount of Stress Perceived by Caregivers Difficulty Moving Around

Stage	M	SD	Range
5	2.00	1.41	1-3
6	3.57	2.88	1-8
7	1.80	1.79	1-5
All Stages	2.87	2.39	1-8

n=14

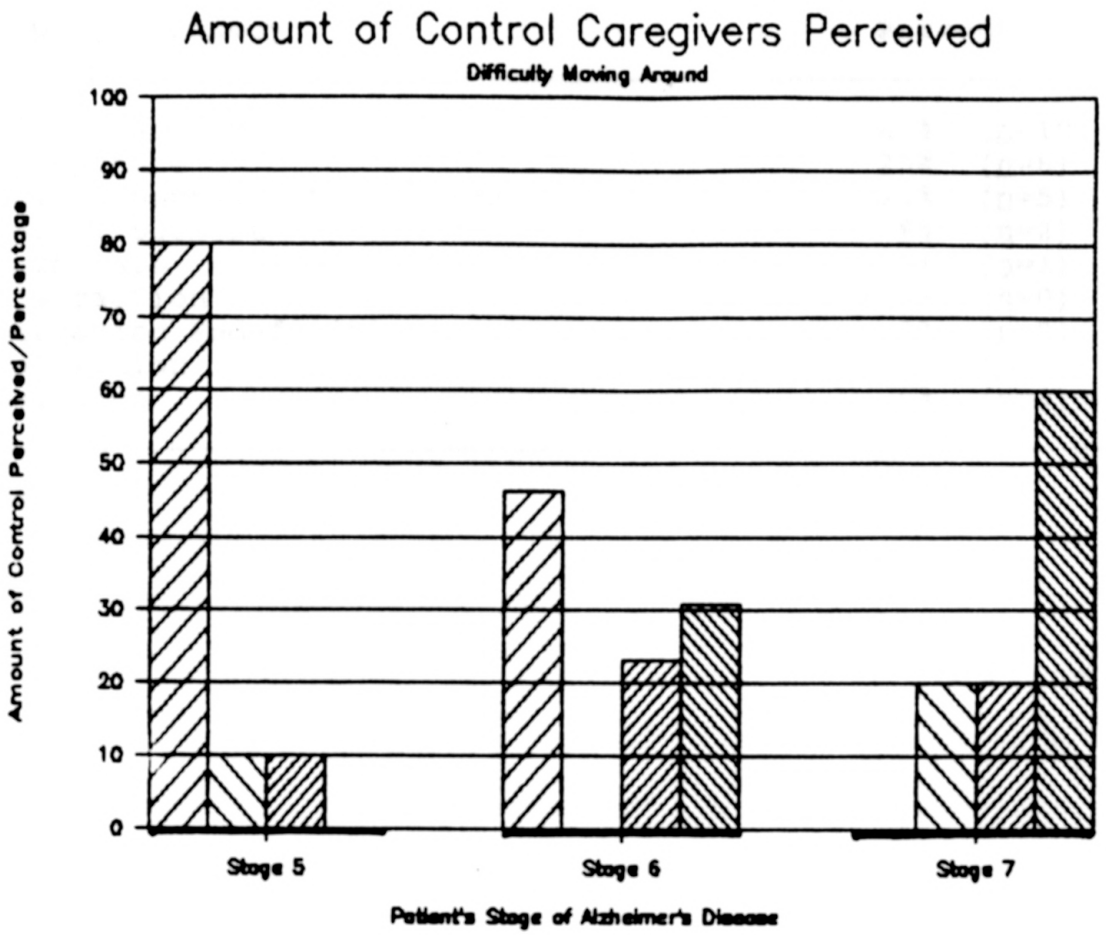
Caregiver Control: Difficulty Moving Around

The Pearson Product Moment correlation coefficient between stress and control ($r=-0.58$, $p=.000$) for the problem of the patient having difficulty moving around indicated significant negative linear relationship between the two variables: greater stress was associated with less control. As shown in Figure 37, the number of caregivers who perceived they had extensive or some control fluctuated throughout the course of the disease, while the number of caregivers who perceived they had no control increased as the stages of the disease progressed. In stage five no caregivers reported perceptions of no control. This percentage rose to approximately 31% in stage six, and by stage seven 60% of the caregivers reported perceptions of no control over handling this problem. However when the differences in control by stage were examined using a Kruskal-Wallis test the results were not statistically significant ($H^1=0.91$, $k=3$, $n=13$).

Frequency of Coping Strategies Used: Difficulty Moving Around

The total number of coping strategies reported for handling the problem of the patient having difficultly moving around was 24. As shown in Table 41, direct action and acceptance were used approximately 67% of the time, and were the two most common coping strategies used for handling

Figure 37



= Problem doesn't apply

= Quite a lot/complete control

= Some control

= No control

Table 41
Rank Order of Coping Strategies Used
Difficulty Moving Around

Coping Strategy	Percentage Used
Direct Action	42% (n=10)
Acceptance	25% (n=6)
Environmental Intervention	21% (n=5)
Social Support	8% (n=2)
Catharsis	4% (n=1)
Distraction	0% (n=0)
Situation Redefinition	0% (n=0)
Relaxation	0% (n=0)
Religion	0% (n=0)

n=14

this problem. The most common direct action taken by caregivers was to help or assist the patient in walking.

Frequency of Environmental Interventions: Difficulty Moving Around

Environmental intervention was the third most common coping strategy employed. For this problem there was not a significant difference in environmental management used by caregivers caring for patients in the last three stages of the disease (H^1=1.91, k=3, $\underline{n}$=13).

When caregivers were asked specifically about their use of environmental interventions for this problem, the most common environmental interventions reported included the following: removing excess furniture and furniture with sharp corners, clearing the traffic path of objects blocking the path such as low tables and area rugs, restricting the patient's area of movement to only safe areas, and providing hand rails on staircases, canes, walkers and wheelchairs. A total of 15 environmental interventions were employed by caregivers with all (100%) of them were reported to have been successful.

Summary of the Use of Environmental Intervention for Coping with the Memory and Behavior Problems

The analyses employed in this chapter examined the frequency of the use of environmental interventions for

coping across all individuals by stage and problem. The analyses documented the total number of environmental interventions employed, and the total number of environmental interventions reported by the caregivers to have been successful.

The smallest percentage of environmental interventions employed by caregivers were reported for the following problems: (1) difficulty grooming self, (2) forgetting what day it was, and (3) difficulty doing simple tasks. These problems generally were not threatening to the patient or caregiver; therefore they may have received less attention in terms of coping strategies. In addition, the problems of the patient having difficulty doing simple tasks and having difficulty grooming have fewer obvious environmental interventions than some other problems, and the reported success of environmental interventions for forgetting the date was low. These problems with few environmental interventions often begin to occur in the early stages of the disease when the caregivers are just learning to handle the problems associated with Alzheimer's disease, and caregivers may not know all the coping strategies available. In the later stages of the disease, when some of the high ranked problems are more frequent, caregivers may be more experienced in finding environmental solutions to problems.

Table 42 rank orders the problems behaviors according to the total number of environmental interventions tried for

Table 42

Rank Order for Number of Environmental Interventions Tried

Problem Behavior	Rank	Number of Environmental Interventions Tried
Dangerous to Self	1	44
Waking Caregiver Up At Night	2	41
Difficulty Bathing Self	3	40
Difficulty Feeding Self	4	30
Difficulty Toileting Self	5	28
Wandering	6	27
Destroying Property	7	18
Losing or Misplacing Things	8.5	17
Difficulty Moving Around	8.5	17
Hiding Things	10.5	16
Difficulty Dressing Self	10.5	16
Forgetting What Day It Is	12	14
Dangerous to Others	13	12
Difficulty Doing Simple Tasks	14	10
Seeing or Hearing Things	15	9
Difficulty Grooming Self	16	2

each problem. The greatest number of environmental interventions were employed for the problems of (1) engaging in behaviors dangerous to self, (2) waking the caregiver up at night and (3) difficulty bathing self. One explanation for the high number of environmental interventions for these problems may be that caregivers employed more environmental interventions to problems that had a specific location toward which to target the interventions. For example, cooking is a problem that could be dangerous to patient and is usually done in the kitchen. Bathing usually occurs in the bathroom, and people usually sleep in bedrooms. Therefore, environmental interventions could be directed to these specific rooms. The following problems didn't usually occur in one specific location and they also had the smallest number of environmental interventions reported: (1) difficulty grooming self, (2) seeing or hearing things, and (3) difficulty doing simple tasks.

Table 43 rank orders the memory and behavior problems according to the percentage of environmental interventions that were reported by the caregivers to have been successful. The largest percentage of successful environmental interventions was shared by the following four problems: (1) hiding things (2) engaging in behavior dangerous to others, (3) difficulty grooming self, and (4) difficulty moving around. The smallest percentage of successful environmental interventions were reported for the

Table 43

Rank Order of Successful Environmental Interventions

Problem Behavior	Rank	Percentage Successful
Hiding Things	2.5	100%
Dangerous to Others	2.5	100%
Difficulty Grooming Self	2.5	100%
Difficulty Moving Around	2.5	100%
Dangerous to Self	5	98%
Difficulty Feeding Self	6	97%
Wandering	7	96%
Waking Caregiver Up At Night	8	92%
Destroying Property	9	89%
Difficulty Bathing Self	10	88%
Difficulty Toileting Self	11	86%
Losing or Misplacing Things	12	82%
Difficulty Dressing Self	13	81%
Difficulty Doing Simple Tasks	14	70%
Seeing or Hearing Things	15	44%
Forgetting What Day It Is	16	14%

following three problems: (1) forgetting the date, (2) seeing or hearing things, and (3) difficulty doing simple tasks. The problems with the highest percentage of successful environmental interventions seem to be those that had the most obvious environmental solutions. For example, if an object creates difficulty for the patient when moving from one room to another, the most obvious solution is to remove that object from the path or find an alternate path. However, for a problem such as the patient seeing or hearing things that are not there, there are fewer obvious environmental interventions for the caregiver to employ, although covering windows to control reflections, removing lifelike photographs and controlling the access to television might be attempted.

When environmental interventions are summarized across stages of the disease, caregivers of patients in the sixth and seventh stages of Alzheimer's disease tried more than twice as may environmental interventions as caregivers for patients in stage five of the disease (see Table 44). The average number of environmental interventions tried per caregiver increased as the stages of the disease progressed, with the caregivers caring for patients in stage seven reporting the highest average number tried (16.8). One explanation for the dramatic increase in the average number of environmental interventions tried in the later stages may be that early in the disease, caregivers may be unaware of

Table 44

Caregiver's Average Use of Environmental Interventions by Stage

Stage	Total Number Tried	Number That Worked	Percentage Successful
Reactive Coping			
4	3.5	3.5	100%
5	5.4	4.3	80%
6	15.1	13.5	89%
7	16.8	14.4	86%
All Stages	11.4	9.9	87%

n=30

the important role the physical environment can play in helping them handle the problems associated with caring for an Alzheimer's disease patient. However, through trial and error caregivers may gradually become more aware of ways they can use the environment as a tool to help them cope. These finding may suggest that early education about the role of the physical environment and suggestions for environmental interventions may help caregivers become better environmental managers. Of the environmental interventions employed by all of the caregivers, approximately 87% were reported to have been successful. The percentage of successful environmental interventions reported by caregivers, across all stages of the disease, fluctuated only slightly between stages and remained consistently high. It is possible, however, that caregiver interventions that failed may have been forgotten more readily, and thus reported with lower frequency.

When the Pearson Product Moment correlations between the frequency of the problem and stress perceived by caregivers were considered across all sixteen memory and behavior problems, eight indicated a significant linear relationship between the two variables (six of which were negative). Most of the significant negative correlations were associated with the problems related the activities of daily living. One possible explanation for this pattern of results may be the unpredictability of these problems in the

earlier stages of the disease. In addition, selection of caregivers able to handle the stress associated with these problems may occur as the disease progresses, with those caregivers unable to handle the stress institutionalizing the patient.

The Pearson Product Moment correlations used to examine the relationships between stress and control for each problem indicated 50% had significant negative linear relationships between the two variables. Most of the significant correlations were associated with problems related to the activities of daily living or with other problems that required much of the caregiver's time or attention. Perhaps, as the stages of the disease progress, the amount of stress perceived by caregivers drops with an increase in acceptance of these problems.

The Kruskal-Wallis tests employed to examine the differences by stage in the amount of stress caregivers perceived, the amount of control, and the environmental management (proportion of environmental interventions employed in relation to the other coping strategies) identified significant differences for some problems. A significant difference in the amount of caregiver-perceived stress by stage was identified for the following three problems: (1) forgetting the date, (2) difficulty bathing self, and (3) difficulty moving around. One possible explanation for this pattern of significant differences is

that when problems occurred frequently they usually required much of the caregiver's time and attention, leading to perceptions of greater stress. Four Kruskal-Wallis tests yielded significant differences by stage for caregivers' perceived control. Significant results were found for the problems of (1) losing or misplacing things (2) forgetting the date, (3) behaviors dangerous to self, and (4) difficulty grooming self. These differences in control may be associated with problems with few obvious solutions or with problems in which many interventions had failed. When the differences in environmental management scores of caregivers by stage of the disease were tested, none of the tests yielded significant differences.

Viewed as a whole, this pattern of findings suggests the importance of considering the changing levels of abilities and types of problems over the course of Alzheimer's disease. Caregivers appear to face different problems and attempt different ways of handling the problems as the disease progresses. Teaching caregivers early in the course of the disease how to manage their environment may be helpful.

CHAPTER FIVE

ROLE OF THE PHYSICAL ENVIRONMENT IN CAREGIVING STRESS

The multiple regression analyses in this section first explore the relationships between characteristics of the caregiver, the environment, and the frequency of the use of environmental management strategies employed by caregivers across all problems and all individuals, and then explore these relationships for each memory and behavior problem. Because of the small sample size (n=30), these analyses were exploratory and the number of variables allowed to enter the regression were limited.

Exploratory Regression Analyses For All Problems Combined

Two sets of multiple regression analyses using a combined fixed and forward step-wise strategy were employed to explore the role of the relative use of environmental versus other coping strategies in (a) the amount of stress experienced by caregivers and in (b) the amount of control perceived by caregivers across all of the problems. For each caregiver, two environmental indices were calculated: the environmental management score and the reactive coping score. A composite environmental management score measured the caregiver's use of environmental intervention in relation to the use of the other coping strategies. This

score was defined as the proportion of problems the caregiver experienced for which he or she chose to use environmental interventions to the total number of problems confronted by the caregiver. The mean composite environmental management score was .50 (SD=.20) with scores ranging from .14 to.81. In addition, the reactive coping score measured the proportion of reactive coping to total coping strategies employed by caregivers. The mean Reactive Coping Score was .48, (SD=.19) with scores ranging from .14 to .81.

Predicting Stress

The dependent variable employed for the first regression analysis was the mean level of stress reported by each caregiver for all of the problems experienced. In addition to the environmental variable, stress may have been related to characteristics of the caregiver and to the control perceived in relation to the problems experienced. Thus, the regression explored the following independent variables in addition to environmental ones: (a) two personal characteristics of the caregiver, the sex of the caregiver and the gender relationship to the patient (same or different sex) and, (b) the amount of control perceived by caregivers for all of the problems encountered.

In the first step, characteristics of the caregiver (sex of the caregiver and same or different sex as the

patient) were entered in a fixed order. After controlling for the two caregiver characteristics, the last three variables were allowed to enter in a forward step-wise fashion. These independent variables were caregiver scores for thee amount of control perceived by caregivers, the relative use of environmental management (coping) strategies, and the proportion of reactive coping strategies to total coping strategies employed by caregivers.

Current research has shown that the relationship between the amount of stress perceived by the caregivers and the effects of the patient's level of disability may be very strong, perhaps masking other independent variables that may influence stress. Thus, the first analysis was completed without including the patient's level of disability. However, a second similar analysis also was completed including the variable measuring the patient's level of disability.

The results of the first analysis are displayed in Table 45. When analyzing all of the problems combined, the results were statistically significant ($F=3.10$, $df=3,26$, $p=.04$). After the variance in caregiver characteristics was accounted for (8%), and additional 18% of the variance in the amount of stress perceived by caregivers could be attributed to the amount of control perceived by the caregivers ($R^2=0.26$, Adjusted $R^2=0.18$).

In the second analysis, the results shown in Table 46

Table 45

Regression Analysis Predicting Mean Stress Perceived by Caregivers

Independent Variables	R2	Adj R2	Beta
Sex of the Caregiver	.01	-0.03	.08
Same/Different Sex as Patient	.08	.01	.17
Control Perceived for All Problems	.26	.18	-.45
Environmental Management	---	---	---
Proportion of Reactive Coping	---	---	---

F=3.10 df=3,26 p=.04**

Table 46

Regression Analysis Predicting Mean Stress Perceived by Caregivers

Independent Variables	R2	Adj R2	Beta
Sex of the Caregiver	.01	-0.03	.06
Same/Different Sex as Patient	.08	.01	.14
Patient's Level of Disability	.16	.06	.17
Control Perceived for All Problems	.29	.18	-.39
Environmental Management	---	---	---
Proportion of Reactive Coping	---	---	---

F=2.55 df=4,25 p=.06

indicated that the independent variables which entered the equation approached but did not attain significance in predicting the amount of stress perceived ($F=2.55$, $df=4,25$, $p=.06$). Neither analysis indicated any significant variance attributed to the environmental variables.

Predicting Control

A similar set of two analyses was completed using the dependent variable of the amount of control caregivers perceived across all of the problems. However, because control was conceptualized as a mediator of stress, the independent variables excluded the amount of stress perceived by the caregivers. The results of the first analysis is shown in Table 47. In the first step, characteristics of the caregiver (sex of the caregiver and same or different sex as the patient) were entered in a fixed order. After controlling for the two caregiver characteristics, the last two variables were allowed to enter in a forward step-wise fashion, the composite environmental management score (the relative use of environmental management strategies), and the reactive coping score (the proportion of reactive coping strategies to total coping strategies employed by caregivers). The variance predicted by the total model ($R^2=0.06$, Adjusted $R^2=-0.01$) was not statistically significant ($F=0.86$, $df=2,27$, $p=.44$). As shown in Table 48, the results of the

Table 47

Regression Analysis Predicting Control Perceived by Caregivers

Independent Variables	**R^2**	**Adj R^2**	**Beta**
Sex of the Caregiver	.01	-0.03	-.13
Same/Different Sex as Patient	.06	-.01	-.23
Proportion of Reactive Coping	---	---	---
Environmental Management	---	---	---

F=0.86 df=2,27 p=.44

Table 48

Regression Analysis Predicting Control Perceived by Caregivers

Independent Variables	**R^2**	**Adj R^2**	Beta
Sex of the Caregiver	.01	-0.03	-.12
Same/Different Sex as Patient	.06	-.01	-.17
Patient's Level of Disability	.14	.04	-.29
Proportion of Reactive Coping	---	---	---
Environmental Management	---	---	---

F=1.45 df=3,26 p=.25

second analysis including the patient's level of disability was not statistically significant ($F=1.45$, $df=3,26$, $p=.25$).

Thus in both cases of stress and control, neither environmental management nor the proportion of reactive coping strategies appear to be predictive. One explanation for these findings may be that the analyses lacked power with only 30 respondents. Second, there may have been too much variability among all of the different problems and their coping responses when they were combined into one group. In other words, the specific coping strategies the caregivers used for particular problems when combined, may not be predictive of the amount of stress or control perceived by the caregivers from all of the problems. One way to address this second question is to conduct similar regression analyses to predict the amount of stress and control on a problem by problem basis.

Multiple Regressions Predicting Stress and Control Perceived by Caregivers for Individual Problems

In view of the failure of the previous analyses to predict summary scores of stress and control, a series of exploratory regression analyses were used to investigate the role of environmental coping strategies in predicting the amount of stress and control experienced by caregivers for each behavior and memory problem.

Predicting Stress

The dependent variable employed in the first set of regression analyses was the level of stress reported by the caregivers for each individual memory and behavior problem. The independent variables selected to explore the role of the physical environment included: the environmental management score, number of environmental interventions tried, and the proportion of environmental interventions that were effective. Since caregiver characteristics accounted for very little variance in the previous analyses and the sample size is quite small, the caregiver characteristics were not included as independent variables in the analyses for individual problems. In the first series the three environmental variables were allowed to enter in a forward step-wise fashion. In each case, only the caregivers reporting the problem were included in the analysis. Since the number of caregivers reporting a problem ranged from 13 to 29, only those problems reported by 15 or more caregivers were analyzed. A total of 14 regression analyses were completed.

For only one problem did any of the environmental variables enter the regression equation. In view of the number of analyses completed, this finding may also be attributed to chance. For the problem of forgetting the date, the proportion of environmental strategies employed in relation to the other coping strategies was a significant

predictor of stress (F=19.17, df=1,26, p=.0002). The second time the series of analysis was completed, in addition to the environmental variables, the patient's level of disability was included since it had accounted for 14 to 16% of the variance in the two previous regression analyses. However, the variable which measured the patient's level of disability was controlled by entering it first, and then the three environmental variables were allowed to enter in a forward step-wise fashion. The results were similar, with the proportion of environmental strategies employed in relation to the other coping strategies being a significant predictor of stress (F=9.35, df=2,25, p=.0009) for the problem of forgetting the date.

Predicting Control

A similar set of analyses was completed using the dependent variable of the amount of control caregivers perceived for individual problems. The three environmental variables were allowed to enter in a forward step-wise fashion. The results of the first series of regression analyses identified only one statistically significant result: the proportion of environmental strategies employed in relation to the other coping strategies was a significant predictor of control for wandering (F=9.84, df=1,18, p=.006). This variable accounted for 35% of the variance.

The second time the series of analysis were completed,

the variable which measured the patient's level of disability was controlled by entering it first, and then the three environmental variables were allowed to enter in a forward step-wise fashion. The results were similar, with the proportion of environmental strategies employed in relation to the other coping strategies being a significant predictor of control ($F=6.23$, $df=2,27$, $p=.0092$) for the problem of wandering. It accounted for 16% of the variance, after 26% had been attributed to the level of disability. This variable may have significantly predicted the amount of control perceived by caregivers with the problem of wandering because this problem has more obvious environmental solutions than many of the other problems. Predicting the amount of control perceived by caregivers for only one problem out of 14 could also have occurred by chance.

The same explanations for the failure of the independent variables in the regression to predict mean stress and control may also hold for these regressions exploring individual problems. For both sets of regression analyses by problem, chance may provide an equally viable explanation of the findings. With a significance level of $p=.05$, it is expected that one in 20 tests will be significant by chance. Thus, the identification of only a few problems for which environmental variables were successful predictors of stress or control suggests that the

use of environmental coping strategies are not related to caregiver perceptions of stress and control.

CHAPTER SIX

RELATIONSHIPS BETWEEN CHARACTERISTICS OF THE CAREGIVER AND THE ENVIRONMENT AND THE USE OF ENVIRONMENTAL COPING STRATEGIES

The role of the physical environment in coping with the problems of Alzheimer's disease varied among caregivers. Some caregivers used very few environmental interventions as a way of handling these problems, while other caregivers frequently used environmental interventions.

Differences in Environmental Management (Reactive Coping)

A series of t-tests were completed to explore whether differences in the environmental management scores of caregivers (based on reactive coping strategies) could be attributed to selected personal characteristics of the caregiver, the patient and/or to the home environment. Caregivers were divided into groups on the basis of the caregiver's sex, relationship to the patient (spouse versus non spouse, same or different sex), the caregivers educational level (those who completed at least some education beyond high school versus those who completed high school or less), and the age of the caregiver (determined by a median split between young and old caregivers). Although the classifications into groups based on being a spouse and

on the patient/caregiver being the same or different sexes were not independent of one another, the exploratory nature of this study warranted the inclusion of both variables in the analysis. As shown in Table 49, none of the five tests examining the differences in caregiver characteristics indicated any significant statistical differences in environmental management scores.

The patient's stage of Alzheimer's disease also was examined as a factor in the extent to which the caregiver employed environmental management strategies. The group of caregivers caring for patients in the earlier (fourth and fifth) stages of the disease relied on environmental interventions significantly less than the caregivers caring for patients in the later (sixth and seventh) stages ($t=-3.85$, $p=.001$). Perhaps through trial and error caregivers become more aware of environmental strategies as the disease progresses.

Additional t-tests explored whether the differences in environmental management scores of caregivers could be attributed to characteristics of the home environment. Caregivers were divided into groups on the basis of home ownership (rent versus own), and the type of dwelling (single family versus non-single family home, one level versus multi-level home). As shown in Table 49, none of the three tests indicated any significant statistical differences in environmental management scores.

Table 49

t-Tests For Differences in the Proportion of Relative Use of Environmental Management

Caregiver Characteristics	t	p
Male vs. Female	0.02	0.98
Spouse vs. Non Spouse	-1.30	0.21
Same Sex vs. Different Sex	1.47	0.15
Educational Level	-1.92	0.07
Age of Caregiver	0.95	0.35
Patient Characteristics		
Stage of Patient's disease	-3.85	0.001**
Housing Characteristics		
Rent vs. Own	-1.05	0.30
Single Family Home vs. Non Single Family Home	-0.56	0.58
One Level vs. Multi-level Home	-0.56	0.58

p=.001**

Differences in Environmental Management (Proactive Coping)

A similar series of t-tests was completed to explore whether differences in proactive coping by caregivers could be attributed to the same personal characteristics of the caregiver, patient and/or to the home environment. As shown in Table 50, the results indicated that caregivers caring for patients of the same sex engaged in a significantly higher proportion of preventative or proactive coping strategies ($t=2.17$, $p=.04$).

Exploratory Multiple Regression Analyses Predicting Environmental Management Scores

In order to explore the possible combined influences of these personal and residential characteristics on environmental management, a multiple regression analysis was completed to predict caregivers' environmental management scores across all problems. Due to the limited sample size, this analysis was exploratory. The dependent variable employed for this regression analysis was the environmental management score, as defined previously. The independent variables selected to explore the environmental characteristics which might influence the environmental management scores were home ownership, residing in single versus multi-family dwellings, and the number of levels in the home. In addition to environmental variables, the environmental management scores may also have been partially

Table 50

t-Tests For Differences in the Proportion of Relative Use of Proactive (Preventative) Environmental Management

Caregiver Characteristics	**t**	**p**
Male vs. Female	0.85	0.40
Spouse vs. Non Spouse	-1.37	0.18
Same Sex vs. Different Sex	2.17	0.04**
Educational Level	-1.49	0.15
Age of Caregiver	1.11	0.28
Patient Characteristics		
Stage of Patient's disease	-1.13	0.27
Housing Characteristics		
Rent vs. Own	-0.06	0.95
Single Family Home vs. Non Single Family Home	-1.25	0.22
One Level vs. Mutli-level Home	-0.45	0.66

p=.04**

attributed to characteristics of the patient and the caregiver. Thus the following independent variables also were included: the patient's level of disability, sex of the caregiver, same or different sex as the patient, caregiver's educational level, and the caregiver's age.

In the first step, the independent variable of the patient's level of disability was entered. After controlling for the patient's level of disability, the characteristics of the caregiver (sex of caregiver, same or different sex of patient, educational level, and the age of the caregiver) were allowed to enter in a forward step-wise fashion. After those variables had been allowed to enter, the independent variables describing the home environment (home ownership, housing type, and number of levels in the home) were allowed to enter in a step-wise fashion.

According to the results of this regression analysis displayed in Table 51, statistically significant variance in caregiver's environmental management could be attributed to the level of the patient's disability (R^2=0.39, Adjusted R^2=0.37, p=.0002). Once variance due to disability had been accounted for, the amount of education the caregiver had received accounted for some additional variance (12%). The total model accounted for 51% of the variance (Adjusted R^2=0.47), and was statistically significant (F=13.98, df=2,27, p=.0001). The role of caregiver education as a predictor in this analysis, despite the failure of the

Table 51

Multiple Regression Analyses Predicting Environmental Management

Independent Variables	R^2	Adj R^2	Beta
Characteristics of the Patient			
Patient level of disability	.39	.37	-.65
Characteristics of the Caregiver			
Sex of Caregiver	---	---	---
Same/Different Sex as Patient	---	---	---
Caregiver's Education	.51	.47	.34
Caregiver's Age	---	---	---
Environmental Characteristics			
Home Ownership	---	---	---
Single or Multi-Family Dwelling	---	---	---
Number of levels in home	---	---	---

F=13.98 df=2,27 p=.0001

t-test to identify differences between those with more than a high school education and those with less education (although the difference approached significance $p=.06$), may reflect a lack of sensitivity to the range of educational levels in the t-test. None of the housing characteristics accounted for additional significant variance in environmental management. Thus age and sex of the caregiver, as well as several characteristics of the home environment, do not appear to influence the environmental management of the caregiver. This finding suggests it may be difficult to target specific groups of people or types of housing where environmental management might best be used. At the same time, these results may suggest that a wide range of caregivers and housing types have potential for employing higher levels of environmental management.

In addition, people with higher levels of education may have more economic, as well as, educational resources to use in coping. (Economic resources were not measured in this study.) These resources may facilitate the use of environmental management, especially if substantial cost are involved (e.g., alarm systems, bathroom modifications, etc.). Perhaps targeting less educated caregivers for informational programs about low cost environmental interventions would insure they are aware of the range of possible environmental solutions that can be employed in coping with the problems associated with caring for an

Alzheimer's disease patient at home.

CHAPTER SEVEN

CONCLUSIONS AND FUTURE RESEARCH

This chapter summarizes the findings, discusses their implications, offers suggestions for environmental interventions to be used by designers and caregivers, and makes recommendations for further research.

Summary of Findings

First Objective

The first objective of this study was to describe the frequency, stress, and control associated with the common memory and behavior problems, caregiver coping strategies, and the role that environmental interventions played in relation to other coping strategies. Caregivers of patients with Alzheimer's disease in the home environment were confronted most frequently by the problems of (a) the patient having difficulty doing simple tasks, (b) losing things, (c) forgetting the date, and (d) difficulty grooming self. The five most frequently reported problems were experienced by 90% or more of the caregivers. The least frequent problem was the patient engaging in behavior dangerous to others, which was reported by 43% of the caregivers.

Caregivers reported that the most stressful memory and

behavior problems included (a) patient engaging in behavior dangerous to self, (b) hiding things, (c) difficulty bathing self, and (d) difficulty dressing self. According to the caregivers, the most stressful problems were those that (1) could endanger the safety and well-being of the Alzheimer's disease patient, (2) took a physical or mental toll on the caregiver, and/or (3) occurred frequently and required much of the caregivers time and attention. The finding that many of the most stressful problems reported by caregivers were those that raised caregiver concerns for the patient' safety or well-being lends support for safety and security as a therapeutic goal (Pynoos et al., 1988; Cohen et al., 1988).

Typically, direct action and acceptance were the first and second most frequent coping strategies employed across all of the caregivers and across all of the problems. The use of the coping strategies of distraction, religion, and relaxation combined made up less than 2% of the coping strategies reported by caregivers. Environmental intervention was reported to have been the third most frequent coping strategy employed for most of the problems, and 87% of the environmental interventions employed were reported by the caregivers to have been successful.

Description of the Differences Between Stages of the Disease

The second objective of the study was to describe the differences between the occurrence of problems and

environmental interventions by stages of the disease. The greatest difference between stages was that caregivers caring for patients in the stages six and seven reported over twice as many environmental interventions as caregivers caring for patients in the fifth stage of the disease. However, the proportion of successful environmental interventions remain fairly consistent throughout the different stages of the disease. Thus, as the course of Alzheimer's disease progresses and the patient's competency declines, aspects of the physical milieu may become increasingly important to the functioning of the patient and/or to reducing the difficulties in caregiving. These findings fit Lawton and Nahemow's (1973) transactional model of competence/press, and in particular the docility hypothesis, since environmental supports must be increased when the Alzheimer's disease patient's competency declines. These findings also lend support to the therapeutic goal of providing an environment that is flexible and adaptable to support the patient's changing needs (Pynoos et al., 1988; Cohen et al., 1988).

The Role of Environmental Interventions

The third objective of this study was to explore the role of environmental interventions in relation to the stress and control perceived by caregivers. Across all of the memory and behavior problems and across all of the

caregivers, the analyses indicate that environmental management (coping) strategies were not significant predictors of the amount of stress and control perceived by the caregivers. When the role of environmental management strategies in predicting the amount of stress and control was examined on a problem by problem basis, only two regression analyses identified environmental strategies as significant predictors of the amount of stress or control. In both sets of analyses, chance is a viable explanation for the few significant findings.

There are many possible explanations for the failure of environmental management strategies to predict caregiver stress and control. First, there may be no significant relationship between stress, control, and environmental management. Second, the analyses may lack power because the study only employed a small number of respondents. Third, the issues affecting the amount of stress and control perceived by caregivers are very complex; thus, the independent variables may not be sufficiently sensitive to predict variation. In other words, the physical environment may play only a small role in stress and control, making it more difficult to identify without more sensitive measures. Fourth, the independent variable of environmental management may not measure accurately the role the physical environment plays. Also, the progression and symptoms of the Alzheimer's disease vary greatly among Alzheimer's disease

patients, making differences by stage difficult to identify. Finally, some of the information obtained on coping strategies was current and some was retrospective (depending on the frequency of the problem), which may have biased reports of environmental efforts.

The environmental interventions employed by caregivers in this study lend support for many of the design principles developed by Pynoos et al., 1988; Cohen et al., 1988; and Cohen and Weisman, in press). These include the following suggestions from Pynoos and his associates' study: (a) appropriate sensory stimulation, (b) security and safety for the individual, (c) appropriate level of activity/task and (d) a flexible and adaptable environment that supports the person's behavior and physical needs. In order to achieve those goals, the types of interventions employed by the caregivers fit within Pynoos and his associates' environmental management strategies of (a) removing or modifying objects, (b) restricting or changing areas, and (c) simplifying tasks and the environment. The most common of Cohen and his associate's (1988) therapeutic guidelines addressed by caregivers in this study included the following: (a) safety and security, (b) support functional abilities and (c) adapt to the changing needs.

Relationship Between Characteristics of the Caregiver, Home, and Environmental Management

The fourth objective explored the relationship between characteristics of the caregiver, the home environment, and the use of environmental management. A series of t-tests explored whether differences in environmental management scores could be attributed to characteristics of the caregiver and/or the home environment. None of the analyses based on caregiver characteristics (e.g. age, sex) indicated any significant difference in environmental management. However, caregivers of patients in the later stages of Alzheimer's disease relied more heavily on environmental strategies than caregiver caring for patients in the earlier stages. These findings fit with Lawton and Nahemow's (1973) transactional model of competence/press, and the docility hypothesis because caregivers employed more environmental interventions as the patients' competence declined. None of the housing characteristics (e.g. ownership, number of levels) indicated any difference in the environmental management scores.

When a multiple regression analysis was employed to predict environmental management scores from caregiver, patient, and housing characteristics, significant variance in environmental management was attributed to the patient's level of disability and the education level of the caregiver. The caregivers' level of education may effect

their incomes, as well as their knowledge, thus indirectly limiting or supporting the cost and/or type of the environmental management strategies they are able to employ.

Strengths and Limitations of the Study

While recognizing it's exploratory nature, this study still makes several contributions. First, most other environmental research has focused on institutional settings, while this study examined the home environments of patients with Alzheimer's disease. Second, although a great deal of research has examined how caregivers cope with the problems associated with caregiving, very little research has focused on the role that the physical environment plays in caregivers' repertoires of coping strategies. For example, environmental interventions would have been included in one of Stone and Neale's (1984) eight coping strategies which encompasses many different types of direct action. In addition, research has failed to explore whether using environmental management increases perceptions of control or decreases stress. The impacts of environmental interventions that have been suggested or tried often have been unknown, although it has been implied that environmental management reduces caregiver stress.

Several limitations of this study also have been identified. First, the small sample size limited the type and the number of analyses that could be conducted, and some

of the analyses that were completed may have lacked sufficient power to identify significant results. Second, this study may not have measured the right variables, or the measures employed by this study may not have been sensitive enough to identify significant results. For example, measuring the amount of difficulty caregivers associated with the occurrence of the memory and behavior problems, in addition to the amount of stress caregivers associated with the problems, may have been more informative. Another limitation stems from the use of stages to characterize Alzheimer's disease. It is difficult at times to distinguish between stages of Alzheimer's disease. Although the symptoms of Alzheimer's disease generally change slowly, a caregiver reporting a problem for the patient in one stage actually may have experienced the problem when the patient was late in the former stage. Thus characterizing patients in terms of caregivers' assessments regarding the stage of Alzheimer's disease may be problematic.

Suggestions for Problem-Focused Environmental Interventions

The final objective of the study was to suggest problem-focused environmental interventions for future caregivers and designers. Because the results of this study do not indicate significant relationships between caregivers' management of the physical environment as a coping strategy and the amount of stress or control they

of the analyses that were completed may have lacked sufficient power to identify significant results. Second, this study may not have measured the right variables, or the measures employed by this study may not have been sensitive enough to identify significant results. For example, measuring the amount of difficulty caregivers associated with the occurrence of the memory and behavior problems, in addition to the amount of stress caregivers associated with the problems, may have been more informative. Another limitation stems from the use of stages to characterize Alzheimer's disease. It is difficult at times to distinguish between stages of Alzheimer's disease. Although the symptoms of Alzheimer's disease generally change slowly, a caregiver reporting a problem for the patient in one stage actually may have experienced the problem when the patient was late in the former stage. Thus characterizing patients in terms of caregivers' assessments regarding the stage of Alzheimer's disease may be problematic.

Suggestions for Problem-Focused Environmental Interventions

The final objective of the study was to suggest problem-focused environmental interventions for future caregivers and designers. Because the results of this study do not indicate significant relationships between caregivers' management of the physical environment as a coping strategy and the amount of stress or control they

however, environmental interventions were only a small percentage of the coping strategies employed for handling this problem. This problem also had the second lowest success rate for the environmental interventions employed. Environmental interventions for handling this problem may not be obvious, may not be location-specific, and may differ by the tasks the patient has difficulty doing. Thus this problem may not prove tractable for environmental management. The following are suggestions for environmental interventions provided by the caregivers:

1. Simplify the task by breaking it task down into smaller steps and eliminate unnecessary steps (e.g. provide a surface to lay out items in the sequence of their use).
2. Direct environmental interventions to specific tasks (e.g. consolidate all canned food in one cabinet to assist the patient in putting them away).
3. Post reminders and memory lists and/or maintain a routine for daily activities.

Difficulty grooming self.

The amount of difficulty a patient had in grooming increased as the disease progressed. Despite the high frequency of this problem, environmental intervention was used by a very low percentage of the caregivers. Some strategies seemed directed toward patient safety, rather than assistance in grooming. The following are environmental interventions most frequently employed by caregivers and found to be helpful:

1. Remove grooming supplies from areas where the patient can gain access to them while unsupervised (safety).
2. Replace the patient's razor blades with an electric

razor (safety).

Forgetting what day it is.

A number of environmental interventions were employed by caregivers for the problem of forgetting the date. These included:

1. Put up big calendars and marking the days off as they passed.
2. Have the patient look at the newspaper and writing down the date,
3. Encourage the patient to look at the date on their watch.
4. Post daily schedules.

Despite the ease and obvious nature of these interventions, they had the lowest success rate of all of the memory and behavior problems studied (14%). The high rate of failure may be attributed to the stage-specific nature of many interventions. The environmental interventions listed above can only work while the patient is still able to read and understand the words and numbers mean. Caregivers reported few opportunities for successful environmental interventions for patients in the later stages of Alzheimer's disease.

Losing or misplacing things.

Losing and misplacing things was frequently occurring problem, especially in the earlier stages while the patient was still mobile and active. Many of the same environmental intentions employed to handle this problem were reported for

the problem of hiding things. They included:

1. Reduce the amount of clutter and the number of items in areas the patient spends most of the time.
2. Put away or storing important, valuable or sentimental items.
3. Post reminders of the locations of certain objects.

Stage Six

In stage six, the frequency of many of the problems increased as the patients' mental reasoning and motor skills declined with the progression of the disease. Although the patients' skills continued to decline, most patients remained mobile and moderately active.

Waking the caregiver up at night.

The second highest number of environmental interventions were reported for the problem of waking the caregiver up at night, with 92% of those interventions reported to have been successful. The high number of environmental interventions employed and their high success rate may be attributed to the location-specific nature of the problem. The environmental interventions reported included the following:

1. Place nightlights in the bedroom or bathroom.
2. Move into separated beds or into separate rooms to sleep.
3. Leave the doors open, or use intercom systems (such as those designed for infants) so that the caregiver can hear when the patient was up.
4. Get a hospital bed or add bars to the patient's bed.
5. Use physical restraints.

Engaging in behavior dangerous to self.

Caregivers employed the highest number of environmental interventions for the problem of the patient engaging in behavior dangerous to themselves. Ninety-eight percent of the environmental interventions employed for this problem were reported to have been successful. The interventions were directed towards the patient's safety. Some of the most commonly reported interventions included the following:

1. Turn off the circuit breaker to the stove and oven, and unplug other appliances when not in use.
2. Hide mechanical and cooking equipment.
3. Remove knobs from the stove.
4. Remove or securely lock away guns, knives, dangerous tools, and toxic substances.

Difficulty Dressing Self.

Because of the complexity of the steps involved in the bathing, it was the fifth most frequent problem reported by caregivers. Although a number of interventions were employed by caregivers only 82% of them were reported to have been successful. Some of the environmental interventions found helpful in the early stages included:

1. Lay out the patient's clothes in the order that they are to be put on.
2. Store frequently worn clothing in the same location.
3. Eliminate the number of items the patient has to choose from.
4. Remove out of season clothing from dressers and closets.

Difficulty bathing self.

The third highest number of environmental interventions were employed for this problem. Of the environmental

interventions employed, 88% were reported to have been successful. The high number of environmental interventions employed for this problem may be attributed to high frequency of the problem, and the location-specific nature of many of the interventions. The following are environmental interventions most frequently employed by caregivers and found to be helpful:

1. Put rubber mats or slip resistent stickers on the bottom of the bathtub.
2. Put a small stool in the tub.
3. Install secure grab bars.
4. Install hand held shower heads.

Stage Seven

In stage seven, because of the complexity of the behaviors associated with the activities of daily living, the frequency of these problems increase. The problems of the patient having difficulty feeding him or herself and difficulty moving around were not prominent until the last stage.

Difficulty feeding self.

Although this was one of the least frequent problems experience, caregivers reported the fourth highest number of environmental interventions tried for it. Of the environmental interventions employed, 97% were reported to have been successful. Some of the most common environmental interventions reported included the following:

1. Replace dinnerware with easy to manage or nonbreakable items (replace glasses with plastic cups with handles).
2. Reduce the number of utensils offered to the patient and limit the number of foods served at a meal.
3. Reduce the noise and clutter from the kitchen and the table.

Difficulty moving around.

Despite the low frequency of this problem, a number of environmental interventions were reported. Many of the interventions were directed toward the patient's safety. These interventions included the following:

1. Remove excess furniture or furniture with sharp corners.
2. Clear the traffic path of objects.
3. Restrict the patient's area of movement to only safe areas.
4. Provide handrails on stairs, canes, walkers, and wheelchairs.

Design Criteria Suggested for Residential Environments for People with Alzheimer's Disease

Cohen et al. (1988) and Pynoos et al. (1988) suggest therapeutic guidelines in order to provide a basis for the planning, programming and design of a variety of environments suited for people with dementia. The following modifications of these therapeutic guidelines suggest interventions targeted specifically to the residential homes of patients with Alzheimer's disease and are based upon the results of this study: These guidelines for the home environment are ranked-ordered, beginning with those of the highest priority to caregivers:

1. Safety and security. (Ensuring the safety and security of the patient was one of the highest priorities behind many interventions reported by the caregivers.)
2. Support functional abilities. (This guideline encompasses interventions needed for the activities of daily living.)
3. Adapt to changing needs. (Caregivers must be able to adapt the environment to the changing physical and social needs of the patient.)
4. Effective coping and management of the caregiver. (An effectively coping caregiver is a very important part of the patient's environment.)

Some of the guidelines developed by Cohen et al. (1988) and Pynoos et al. (1988), have been omitted from this modified list because they may not apply to the home environment or they have lower priority based on caregiver reports. For example, the therapeutic goal of awareness and orientation (Cohen et al., 1988) becomes a less of a priority for caregivers as the disease progresses. Also, the home environments are typically stimulating and complex, therefore the concern typically becomes reducing excessive stimulation. It is important to note that the priority of these goals for the caregivers may shift over the course of the disease. for example, privacy may not become a priority until the patient begins to have difficulty sleeping, toileting or bathing. In addition, when the patient remains

in the home, there may be a gradual transition from the patient having primary control to secondary control.

The environmental interventions employed by caregivers in this study lend support for many of the design principles developed by Pynoos et al. (1988). The design principles most supported by this study, which were targeted towards the home environments of Alzheimer's disease patients, included the following:

(1) Provide appropriate sensory stimulation.

(2) Provide security and safety for the individual.

(3) Provide appropriate level of activity/task.

(4) Be flexible and adaptable in supporting the person's behavior and physical needs.

In order for the patient's environment to meet these criteria, the following modifications to the environmental management strategies may address residential environments in particular:

(1) Removing or modifying objects and providing sufficient storage.

(2) Restricting or changing an area.

(3) Introducing low cost and/or reversible environmental modifications.

(4) Simplifying tasks and the environment.

(5) Providing appropriate environmental and sensory stimulation.

Future Research Recommendations

The results and recommendations of this study suggest several issues for further research. First, the limitations imposed on this study by the small number of respondents mean that findings need to be replicated with a larger sample. Second, this study took a cross sectional approach. Depending on the frequency of the problems, some of the data reported by caregivers was retrospective. This research design does not address how these patients and caregivers change over the different stages of the disease. Thus future research should focus on currently experienced problems, on the coping strategies which have been employed in the immediate past, and follow the caretakers and the patients over time. One reason this is important is because Stone and Neale (1984) found a different pattern of coping when coping was reported retrospectively instead of currently.

There also appears to be a substantial lack of awareness of the range of environmental solutions that are possible, because many of the caregivers interviewed had very little information on environmental management strategies. The present study examined the role of environmental coping strategies in relation to other caregiver coping strategies. Future research should focus more directly on the use of environmental intervention, because many small environmental interventions are

overlooked or not perceived by the caregiver as environmental management (e.g. removing a throw rug, or closing a door). As a result, many caregivers employ environmental interventions, but do not consciously acknowledge the fact that they have done so. If caregivers become more aware of how they already use their environments, and of ways they can change the environment to make caregiving easier, they may be able to use the environment more effectively.

Another recommendation is to develop an idea book of low-cost modifications (based on existing research) that could be implemented by the caregiver without the outside help of contractors or designers. Future research could employ a before-and-after study in order to evaluate the use and effectiveness of the low-cost modifications and environmental strategies recommended. If such strategies were shown to be effective, environmental idea books could be distributed through local Alzheimer's disease support groups and physicians' offices.

The needs of Alzheimer's disease patients are constantly changing and many of the environmental interventions employed are temporary in nature. In many cases, even the situation of the patient living in the home may be short-term. Thus, many caregivers are reluctant to make changes or modifications in the environment because the patient may be admitted to a nursing home in the future.

Therefore, future research needs to pay particular attention to low cost, reversible environmental management strategies for existing structures, and to the acceptance of these changes by caregivers and their families. Finding ways to retrofit existing home environments is important because designing new homes for Alzheimer's disease patients (excluding group homes) usually is not practical and many caregivers are reluctant to move.

Much of the past research has taken a "one size fits all" approach to the design of environments for Alzheimer's disease patients. However, due to the changing nature of the disease, caregivers are constantly faced with different problems. Future research is needed to make a more fine-grained analyses of the occurrence of problems over time and their possible solutions in order to make specific recommendations for change over the course of Alzheimer's disease. Research also should examine the amount of adaptability in home environments and how it affects the amount of environmental management the caregivers employ.

Another area for further research is identifying what benefits are expected from the employment of environmental management strategies, along with the goals to be achieved. For example, this study did not ask about caregiver perceptions of the difficulty of care. Perhaps, the goal of environmental management should be to make caregiving less difficult instead of relieving stress.

This study examined the role of the physical environment in the caregivers' repertories of coping strategies used to handle the problems associated with the care of Alzheimer's disease patients in the home. The results of this study indicate that environmental intervention was the third most frequent coping strategy reported. It was used not only to respond to the problems caregivers encountered, but also proactively, in attempt to prevent certain problems from occurring. Despite the frequency of use of environmental interventions, relatively few caregivers initially reported environmental intervention as a way of coping. Although the study is exploratory, the results suggest that the use and the high rate of effectiveness of the environmental interventions reported indicate the potential for teaching caregivers to be better environmental managers. Identifying the impacts of such environmental management on caregivers themselves will require further research.

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Appendix A

Therapeutic Goals

1. **Safety and Security:** Ensuring that users sustain no harm is the first imperative of any therapeutic environment.
2. **Support functional abilities:** The maintenance of functional abilities not impaired by disease, as in performance of the activities of daily living, can have important and positive implications for the sense of competence and self-esteem of people with dementia.
3. **Awareness and orientation:** Program, policy and design should all assist people with dementia in "knowing where they are."
4. **Stimulation and challenge:** People with dementia may not be able to process high levels of stimulation with out experiencing overload and distress: conversely, many institutional settings represent a degree of sensory and social deprivation that is clearly not therapeutic.
5. **Privacy and control:** People with dementia should, to the greatest extent possible, have the ability to make decisions and to take responsibility for their own lives and environments.
6. **Adapt to the changing needs:** It is essential to respond to changing patient needs and evolving therapeutic approaches and to determine the level of ability a given therapeutic facility is capable of handling.
7. **The healthy and familiar:** Patients with dementia are confronted with an on-going series of changes in themselves and their world. Thus it is important, to the extent possible, to maintain their ties to that with which they are familiar and comfortable.

*Source: Cohen et al. (1988).

Strategies for Environmental Management

1. **Removing or Modifying Objects:** In order to make the home safer for both the person with Alzheimer's Disease and the household, it may be necessary to remove hazards and objects that are potentially dangerous. examples include sharp objects, poisonous materials, trailing wires or cords, loose mats, unsteady furniture, medications or guns. Appliances that can no longer be used safely may have to be removed or modified. If a person is continually losing objects (e.g., keys) the caregiver may consider making up several sets, hiding a spare or providing the person with a substitute model.

2. **Enriching Home Like Environment and Increasing Familiarity:** While objects may need to be removed if a room is too crowded, it is important to maintain familiarity of the setting for the demented person. If, for example, unsteady furniture is removed it is important that it be replaced by an appropriate substitute, particularly if it supports the person's walking through a room. Through the use of sensory stimulation and cues, the home environment can be enriched and used as a support in increasing the person's need for familiarity (e.g., cooking smells, photos albums of family, pictures of familiar scenes on the wall, flowers, the texture of a favorite fabric). When there is a need to reinforce awareness of a particular room, increasing familiarity and location might be done through the use of color, a sign and/or a picture of the room.

3. **Introducing Environmental Modifications:** Some aides can be introduced to make the environment safer and more supportive (e.g., grab bars, railings on the stairs, a raised toilet seat, eating utensils). Other modifications can be made so that the home fits the person's behavioral needs (e.g., providing shades that can control afternoon glare that otherwise may result in restlessness).

4. **Providing Appropriate Environmental and Sensory Stimulation:** If the person is feeling agitated, bored or restless it may be helpful to remove the person to another setting that provides appropriate sensory stimulation. A room can provide too much stimulation or too little. For example, if a room is particularly noisy and the person is becoming agitated, moving him/her to a quieter room and playing soothing music may be effective. Giving the person a foot or hand

massage in warm water can also produce a calming effect as well as provide important tactile stimulation. If the person appears to be bored, moving him/her to a room with views onto street activity or providing a fish tank or a bird in a cage may add interest.

5. **Diverting Attention:** Diverting the person's attention through the introduction of a familiar or enjoyable activity rather than exhibiting anger or annoyance at a specific act may decrease some problem behaviors. When boredom or inactivity exists, presenting an activity that is appropriately complex for the person's ability and that arises out of a person's past history and interests can be helpful. For example, if the person was a cashier, providing him/her with coins to sort might be an appropriate type of activity.

*Source: Pynoos et al. (1988).

Appendix C

Telephone Interview

SUBJECT'S NAME: _____ SUBJECTS ID: __
SUBJECT'S ADDRESS: _____
SUBJECT'S TELEPHONE NUMBER: _____

Hi, my name is Kay Welsh. I am a student at Kansas State University working on my masters degree in architecture. I would like to interview you to ask you some questions. These questions will include information about what types of memory and behavior problems that you, as the caregiver of an Alzheimer's disease patient, have encountered. I am also interested finding out the ways in which you have handled these problems.

But first of all, I need to ask you a few questions to see if you are eligible for the study. Depending on your answers to the first few questions, I may not need to ask you any additional questions.

1. What is your relationship to your relative?
   a. daughter
   b. wife
   c. husband
   d. daughter-in-law
   e. son
   f. sister
   g. brother
   h. granddaughter
   i. other(specify)_____

2. Do you and your relative reside in the same residence?
   a. yes b. no

   (If yes, skip to question #5)

3. If no, have you and your relative recently lived in the same residence together? a. yes b. no

   (If no, skip to question #5)

4. If yes, how long has your relative not lived at the same residence with you? _____

5. What percent of patient care are you personally responsible for?
   a. less than 50%
   b. between 50 and 75%
   c. between 75 and 100%
   d. all

6. Has a medical doctor diagnosed your relative as having Alzheimer's disease? a. yes b. no

INTERVIEW DATE:_____ INTERVIEW TIME:_____

Appendix D

Cover Letter

Dear Caregiver,

My name is Kay Welsh, and I am a student at Kansas State University working on my masters degree in Architecture. I have chose to study the home environments of Alzheimer's disease patients for my thesis. Currently there has been a lot of research about the care of Alzheimer's disease patients in institutional settings, such as hospitals and "special care" facilities. This research is very important because Alzheimer's disease is a major cause of institutionalization. However, as many as two-thirds of all dementia patients are cared for in the home. For this reason, understanding how people care for a person with dementia, who lives at home, is also very important. Until the causes or cures of this disease are found, helping the patients and their families with practical questions, and the development of interventions and management techniques become key issues.

In order to complete this research, I plan to interview 30 caregivers of Alzheimer's disease patients currently caring for their loved ones in the home. I would greatly appreciate your help in participating in an interview. The questions in the interview will include information about what types of memory and behavior problems that you, as the caregiver of an Alzheimer's disease patient, have encountered, and the ways in which you have handled these problems.

The goal of my research is to identify early and appropriate changes that can be made in the home environment that may help individuals and families providing care for Alzheimer's disease patients manage the stresses of caregiving more effectively and help them provide better care at home.

Of course, your participation is voluntary, and any information you share with me will remain confidential. This means that no one will be able to find out how you answered any of the questions. You may choose not to answer a question if you wish, or discontinue the interview at anytime. Also if you have any questions about your rights as a participant in this study, you may contact Lyn Norris-Baker, Architecture and Design Subcommittee for Protection of Human Subjects, Seaton 211, Kansas State University, Manhattan, KS, (913) 532-5953.

I realize that your time is limited and very valuable. If you decide to help me, I will be happy to share what information I know from past research and the findings from my study. If you think you could help me, or would like more information about participating, please return the

attached information sheet as soon as possible. Thank you for your help! If you have any questions or concerns, please feel free to contact me at the address below.

Sincerely,

Kay Welsh
1904 Indiana Lane
Manhattan, KS 66502
(913) 539-2777

Kay Welsh

Appendix E

Questionnaire

Subject Interview Subject ID _____

Informed Consent

Most people would agree that our home environment is important when we think of everyday activities. The home environment becomes even more important to the caregiver caring for an elderly Alzheimer's disease patient. I am a student at Kansas State University presently working on a masters degree in architecture. The results of this interview will be used to develop ways to improve the home environments of Alzheimer's disease patients and their families.

I would like you to answer some questions about the memory and behavior problems that you, as a caregiver of an elderly Alzheimer's disease patient, have encountered. These questions will include information about the frequency of problem behaviors, your feelings and the ways in which you have handled these problems. There should be no risk to you, and your participation is completely voluntary. If you prefer not to answer a question, that's fine. Answering the questions should take about 1 hour.

Of course, any information you share with me will remain confidential. This means that no one will be able to find out how you answered any of these questions. Also if you have any questions about your rights as a participant in this study, you may contact Lyn Norris-Baker, Architecture and Design Subcommittee for Protection of Human Subjects, seaton 211, Kansas State University, Manhattan, KS, (913) 532- 5953.

If you agree to help me, you can feel free to discontinue the interview at any time and feel free to ask me any questions you may have during the interview. The time you spend to answer my questions will be greatly appreciated.

Subject's signature _____ Date _____

Background Information Questionnaire Subject ID ___

Patient Background

1. Sex:
   a. Male
   b. Female

2. Race:
   a. Caucasian
   b. Black
   c. Other (specify) _____

3. Age: _____ years

4. Approximately how long would you say your loved one has had alzheimer's disease? _____

5. Who does the patient live with (check as many as apply)?
   a. Spouse
   b. Sibling
   c. Children
   d. Grandchildren
   e. Other (specify) _____

Caregiver Background

6. Sex:
   a. Male
   b. Female

7. Race:
   a. Caucasian
   b. Black
   c. Other (specify) _____

8. Age: _____ years

9. Marital Status:
   a. Married
   b. Single
   c. Widowed
   d. Divorced

10. Employment:
    a. Employed part time
    b. Employed full time
    c. Retired
    d. Homemaker

11. Education:
    a. Below high school graduate
    b. High school graduate
    c. Tech school/Junior college graduate
    d. 4 year college graduate or above

Home Environment Background

13. Type of housing:
    a. Rent
    b. Own
    c. Other (specify) _____

14. Type of housing:
    a. Apartment
    b. Duplex
    c. Single family detached house
    d. Other (specify) _____

15. How many floors (levels) does your residence have?
    _____

16. How long have you lived in current residence?
    _____

17. How long has your impaired relative lived in current residence?
    a. Less than 1 year
    b. Between 1 and 5 years
    c. 10 years or more
    d. Always lived there

Characteristics of the Patient

INSTRUCTIONS:
Say to the caregiver "There are many different stages of Alzheimer's disease. The next few questions will be used to identify your relative's current condition.

A. Is your relative disorientated to time or place?
    a. yes b. no

    (If yes, skip to question #E)

B. Is your relative able to do complex tasks (such as handling money transactions or writing checks)?
    a. yes b. no

    (If no, skip to question #D)

C. If yes, read cards A and B, and tell me which of the two stages best describes your relative's current condition?
a. A b. B

D. If no, read cards B and C, and tell me which of the two stages best describes your relative's current condition?
a. B b. C

E. Is your relative able to dress, bathe and toilet themselves? a. yes b. no

(If no, skip to question #G)

F. If yes, read cards C and D, and tell me which of the two stages best describes your relative's current condition?
a. C b. D

G. If no, read cards D and E, and tell me which of the two stages best describes your relative's current condition?
a. D b. E

18. Stages of relative's current condition.

a. Level A
b. Level B
c. Level C
d. Level D
e. Level E

Alzheimer's Disease Stages

A.
- * cognitive deficits apparent to intimates and associates
- * patient tries to deny and hide cognitive impairments
- * patient develops anxiety about symptoms
- * difficulty performing in demanding work and social situations
- * job performance declines
- * difficulty remembering what they read or are told
- * difficulty finding the right word in conversation

B.
- * person does not admit to experiencing any problems
- * difficulty in knowing current or recent events
- * no difficulty with time orientation
- * able to travel to familiar locations
- * less able to handle finances and marketing
- * complex tasks may be overwhelming (withdraws from challenging situation)

C.
- * difficulty with recalling information about major aspects of their past (address, names of grandchildren)
- * disorientated to time or to place
- * able to retain facts about themselves an close relatives (spouse, children)
- * no assistance required with toileting or eating
- * less able to choose proper clothing
- * may need encouragement to bathe

D.
- * occasional difficulty remembering spouse's name
- * able to remember their own name most of the time
- * able to recall some knowledge of past events
- * unaware of surroundings (time and place)
- * less able to travel to familiar locations (usually requiring a travel escort)
- * daily activities are frequently disturbed
- * progressive decline in personal hygiene (difficulty in dressing, bathing, toileting, urinary incontinence, fetal incontinence)

E.
- * speech and motor abilities are minimal or lost (limited vocabulary, unable to walk)
- * patient is incontinent of both urine and bowel
- * requires assistance with toileting and feeding
- * completely bedridden

* Source: Reisburg (1985).

INSTRUCTIONS:

Please read the following scale and circle the letter which best describes your relatives current level of functional ability.

Physical Self-Maintenance Scale

19. **Toileting**

a. Cares for self at toilet completely, no incontinence.
b. Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most accidents).
c. Soiling or wetting while asleep more than once a week.
d. Soiling or wetting while awake more than once a week.
e. No control of bowels or bladder.

20. **Feeding**

a. Eats without assistance.
b. Eats with minor assistance at meal times and/or with special preparation of food, or help in cleaning up after meals.
c. Feeds self with moderate assistance and is untidy.
d. Requires extensive assistance for all meals.
e. Does not feed self at all and resists efforts of others to feed him.

21. **Dressing**

a. Dresses, undresses, and selects clothes from own wardrobe.
b. Dresses and undresses self, with minor assistance.
c. Needs moderate assistance in dressing or selection of clothes.
d. Needs major assistance in dressing, but cooperates with efforts of others to help.
e. Completely unable to dress self and resists efforts of others to help.

22. **Grooming** (neatness, hair, nails, hands, face, clothing)

a. Always neatly dressed, well-groomed, without assistance.
b. Grooms self adequately with occasional minor assistance, e.g. shaving.
c. Needs moderate and regular assistance or supervision in grooming.
d. Needs total grooming care, but can remain well-groomed after help form others.
e. Actively negates all efforts of others to maintain grooming.

23. **Physical Ambulation**

a. Ambulates within residence
b. Ambulates with assistance of (circle one)
    1. another person
    2. railing
    3. cane
    4. walker
    5. wheel chair
        a. Gets in and out without help.
        b. Needs help in getting in and out.
c. Sits unsupported in chair or wheelchair, but cannot propel self without help.
d. Bedridden more than half the time.

24. **Bathing**

a. Bathes self (tub, shower, sponge bath) without help.
b. Bathes self with help in getting in and out of tub.
c. Washes face and hands, but cannot bathe rest of body.
d. Does not wash self but is cooperative with those who bathe him.
e. Does not try to wash self and resists efforts to keep him clean.

* Source: Lawton and Brody (1969).

Memory and Behavior Checklist

INSTRUCTIONS:

Say to the caregiver: "I am going to read you a list of common problems. Please tell me if any of these problems have occurred during the past week. If the problem has ever occurred or has occurred in the past week, there are some additional questions I will want to ask you about the situation."

25. How often in the past week has the problem of the person wandering or getting lost occurred?
    a. never occurred
    b. has occurred, but not in the past week
    c. has occurred 1 or 2 times in the past week
    d. has occurred 3 to 6 times in the past week
    e. occurs daily or more often
    f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

    (If "a", skip to question #28)
    (If "b", skip to question #27)

26. How much control did you feel you have in handling the problem?
    a. quite a lot/complete b. some c. none

27. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

28. How often in the past week has the problem of the person hiding things (such as money or jewelry) occurred?
    a. never occurred
    b. has occurred, but not in the past week
    c. has occurred 1 or 2 times in the past week
    d. has occurred 3 to 6 times in the past week
    e. occurs daily or more often
    f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

    (If "a", skip to question #31)
    (If "b", skip to question #30)

29. How much control did you feel you have in handling the problem?
    a. quite a lot/complete b. some c. none

30. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

31. How often in the past week has the problem of the person losing or misplacing things occurred?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #34)
(If "b", skip to question #33)

32. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

33. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

34. How often in the past week has the problem of the person forgetting what day it is occurred?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #37)
(If "b", skip to question #36)

35. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

36. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

37. How often in the past week has the problem of the person destroying property occurred?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #40)
(If "b", skip to question #39)

38. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

39. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

40. How often in the past week has the problem of the person waking you up at night occurred?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #43)
(If "b", skip to question #42)

41. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

42. On a scale from 1 to 10, how stressful would you rate the problem or situation? _____

43. How often in the past week has the problem of the person engaging in behaviors potentially dangerous to others occurred?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #46)
(If "b", skip to question #45)

44. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c.none

45. On scale from 1 to 10, how stressful would you rate the problem or situation? _____

46. How often in the past week has the problem of the person engaging in behaviors potentially dangerous to him or herself occurred?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #49)
(If "b", skip to question #48)

47. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

48. On a scale from 1 to 10, how stressful would you rate the problem or situation? _____

49. How often in the past week has the problem of the person seeing or hearing things that are not there (such as hallucinations or illusions) occurred?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #52)
(If "b", skip to question #51)

50. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

51. On a scale from 1 to 10, how stressful would you rate the problem or situation? _____

52. How difficult is it for your relative to do simple tasks (such as putting the groceries away or simple repairs)?
a. not difficult b. somewhat difficult c. very difficult

53. How often does he/she need help or assistance in doing simple tasks?
a. none of the time c. most of the time
b. some of the time d. all of the time

54. How often in the past week has your relative had difficulty doing simple tasks?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #57)
(If "b", skip to question #56)

55. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

56. On a scale from 1 to 10, how stressful would you rate the problem or situation? _____

57. How difficult is it for your relative to dress him/herself (either partially or totally)?
a. not difficult b. somewhat difficult c. very difficult

58. How often does he/she need help or assistance in getting dressed?
a. none of the time
b. some of the time
c. most of the time
d. all of the time

59. How often in the past week has your relative had difficulty in dressing him/herself?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #62)
(If "b", skip to question #61)

60. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

61. On as scale from 1 to 10, how stressful would you rate this problem or situation? _____

62. How difficult is it for your relative to feed him/herself?
a. not difficult b. somewhat difficult c. very difficult

63. How often does he/she need help or assistance in feeding him/herself?
a. none of the time
b. some of the time
c. most of the time
d. all of the time

64. How often in the past week has the person had difficulty feeding him/herself?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #67)
(If "b", skip to question #66)

65. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c.none

66. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

67. How difficult is it for your relative to toilet him/herself?
a. not difficult b. somewhat difficult c. very difficult

68. How often does he/she need assistance or help in toileting ?
a. none of the time
b. some of the time
c. most of the time
d. all of the time

69. How often in the past week has the person had difficulty toileting him/herself?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #72)
(If "b", skip to question #71)

70. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. no control

71. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

72. How difficult is it for your relative to bathe or shower him/herself?
a. not difficult b. somewhat difficult c. very difficult

73. How often does he/she need assistance or help in bathing or showering?
a. none of the time
b. some of the time
c. most of the time
d. all of the time

74. How often in the past week has the person had difficulty in bathing or showering him/herself?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #77)
(If "b", skip to question #76)

75. How much control did you feel you have over handling the problem?
a. quite a lot/complete b. some c. none

76. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

77. How difficult is it for your relative to groom him/herself (for example: hair, neatness, nails, face, clothing)?
a. not difficult b. somewhat difficult c. very difficult

78. How often does your relative need assistance or help in grooming him/herself?
a. none of the time
b. some of the time
c. most of the time
d. all of the time

79. How often in the past week has the person had difficulty in grooming him/herself?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #82)
(If "b", skip to question #81)

80. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

81. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

82. How difficult is it for your relative to move around within the residence?
a. not difficult b. somewhat difficult c. very difficult

83. How often does your relative need assistance or help in moving around within the residence?
a. none of the time
b. some of the time
c. most of the time
d. all of the time

84. How often in the past week has the person had difficulty moving around within the residence?
a. never occurred
b. has occurred, but not in the past week
c. has occurred 1 or 2 times in the past week
d. has occurred 3 to 6 times in the past week
e. occurs daily or more often
f. would occur if not supervised by caregiver (e.g. wandering except door is locked)

(If "a", skip to question #87)
(If "b", skip to question #86)

85. How much control did you feel you have in handling the problem?
a. quite a lot/complete b. some c. none

86. On a scale from 1 to 10, how stressful would you rate this problem or situation? _____

87. other _____
_____

88. other _____
_____

Frequency Ratings

A= never occurred

B= has occurred, but not in past week

C= has occurred 1 or 2 times in past week

D= has occurred 3 to 6 times in past week

E= occurs daily or more often

F= would occur if not supervised by caregiver
(e.g. wandering except door is locked).

Control Ratings

A= Quite a lot/Complete
B= Some
C= No control

Stress Rating

A scale from 1 to 10 (where 10 is the death of a friend or relative and 1 is a minor annoyance).

minor annoyance death of friend/relative

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

Difficulty Rating

A= Not difficult
B= Somewhat difficult
C= Very difficult

Occurrence Rating

A= None of the time
B= Some of the time
C= Most of the time
D= All of the time

Intervention Intention

A= prevention:	prevent and accident or problem behavior from occurring. (ex. lock door to prevent person from wandering)
B= rehabilitation:	to help improve or restore a person's present level of functioning. (ex. the problem of not making it to the bathroom at night just beginning -move person into a bedroom closer to the bathroom and the person is able to get there on time again)
C= maintenance:	help maintain a person's present level of functioning. (ex. before person has a problem making it to the bathroom on time, move them to a bedroom close to the bathroom, or replace a chair that is hard to get out of for one which is easier to get out of)
D= help caregiver:	help make things easier on the caregiver. (ex. move person to a bedroom near the caregivers for easier nighttime observation)
E= other (specify)	_____

Description of the Coping Categories

Category	Definition
1. Distraction	Diverted attention away from the problem by thinking about other things or engaging in some activity.
2. Situation Redefinition	Tried to see the problem in a different light that made it seem more bearable.
3. Environmental Intervention	Thought about physical environmental solutions to the problem, gathered information about it, or actually changed something in the environment to try to solve it.
4. Direct Action	Thought about non-environmental solutions to the problem, gathered information about it, or actually did something to try solve it.
5. Catharsis	Expressed emotions in response to the problem to reduce tension, anxiety, or frustration.
6. Acceptance	Accepted that the problem had occurred, but that nothing could be done about it.
7. Seeking social support	Sought or found emotional support from loved ones, friends, or professionals.
8. Relaxation	Did something with the implicit intention of relaxing.
9. Religion	Sought or found spiritual comfort and support.
10. Other (Specify)	_____

Description of the Coping Categories

INSTRUCTIONS: Say to the caregiver: Coping can be defined as "those behaviors and thoughts which are consciously used by an individual to handle or control the effects of anticipating or experiencing a stressful situation" (Stone and Neale, 1987, p. 893). Listed below are nine coping categories and their definitions. Please read them carefully. Choose as many as apply.

Behaviors **Coping Strategies**

89. How have you handled the problem of the person wandering or getting lost? 1 2 3 4 5 6 7 8 9 10

107. Have you thought about physical environmental solutions to the problem of the person wandering or getting lost, gathered information on it, or actually changed something in the environment?
a. yes b. no

108. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

109. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

110. Is it working? a. yes b. no

90. How have you handled the problem of the person hiding things (e.g. money, jewelry)? 1 2 3 4 5 6 7 8 9 10

111. Have you thought about physical environmental solutions to the problem of the person hiding things, gathered information on it, or actually changed something in the environment?
a. yes b. no

112. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

113. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

114. Is it working? a. yes b. no

91. How have you handled the problem of the person losing or misplacing things? 1 2 3 4 5 6 7 8 9 10

115. Have you thought about physical environmental solutions to the problem of the person losing or misplacing things, gathered information on it, or actually changed something in the environment?
a. yes b. no

116. If environmental intervention has been used to handle this problem describe the environmental solution tried?

117. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

118. Is it working? a. yes b. no

92. How have you handled the problem of the person forgetting what day it is? 1 2 3 4 5 6 7 8 9 10

119. Have you ever thought about physical environmental solutions to the problem of the person forgetting what day it is, gathered information on it, or actually changed something in the environment to try and solve this problem? a. yes b. no

120. If environmental intervention has been used to handle this problem describe the environmental solution tried?

121. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

122. Is it working? a. yes b. no

93. How did you handle the problem of the person destroying property? 1 2 3 4 5 6 7 8 9 10

123. Have you ever thought about physical environmental solutions to the problem of the person destroying property, gathered information on it, or actually changed something in the environment to solve this problem? a. yes b. no

124. If environmental intervention has been used to handle this problem describe the environmental solution tried?

125. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify)_____

126. Is it working? a. yes b. no

94. How did you handle the problem of the person waking you up at night? 1 2 3 4 5 6 7 8 9 10

127. Have you ever thought about physical environmental solutions to the problem of the person waking you up at night, gathered information on it, or actually changed something in the environment to try to solve this problem?a. yes b. no

128. If environmental intervention has been used to handle this problem describe the environmental solution tried?

129. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify)_____

130. Is it working? a. yes b. no

95. How did you handle the problem of the person engaging in behavior potentially dangerous to self? 1 2 3 4 5 6 7 8 9 10

131. Have you thought about physical environmental solutions to the problem of the person engaging in behaviors potentially dangerous to themselves, gathered information on it, or actually changed something in the environment to try to solve this problem? a. yes b. no

132. If environmental intervention has been used to handle this problem describe the environmental solution tried?

133. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify)_____

134. Is it working? a. yes b. no

96. How did you handle the problem of 1 2 3 4 5 6 7 8 9 10
the person engaging in behavior potentially dangerous to others?

135. Have you thought about physical environmental solutions to the problem of the person engaging in behavior potentially dangerous to others, gathered information on it, or actually changed something in the environment to try to solve this problem?
a. yes b. no

136. If environmental intervention has been used to handle this problem describe the environmental solution tried?

137. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify)_____

138. Is it working? a. yes b. no

97. How did you handle the problem of 1 2 3 4 5 6 7 8 9 10
the person seeing or hearing things that are not there (hallucinations or illusions)?

139. Have you thought about physical environmental solutions to the problem of the person seeing or hearing things that are not there, gathered information on it,or actually changed something in the environment to try to solve this problem?
a. yes b.no

140. If environmental intervention has been used to handle this problem describe the environmental solution tried?

141. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

142. Is it working? a. yes b. no

98. How have you handled the problem of the person having difficulty in doing simple tasks (e.g. put groceries away, simple repairs)? 1 2 3 4 5 6 7 8 9 10

143. Have you thought about physical environmental solutions to the problem of the person doing simple tasks, gathered information on it, or actually changed something in the environment to try to solve this problem? a. yes b. no

144. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

145. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

146. Is it working? a. yes b. no

99. How have you handled the problem of the person having difficulty in dressing self (either partially or totally)? 1 2 3 4 5 6 7 8 9 10

147. Have you thought about physical environmental solutions to the problem of the person having difficulty dressing themself, gathered information on it, or actually changed something in the environment to try to solve this problem?
a. yes b. no

148. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

149. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

150. Is it working? a. yes b. no

100. How have you handled the problem of the person having difficulty in feeding self? 1 2 3 4 5 6 7 8 9 10

151. Have you thought about physical environmental solutions to the problem of the person having difficulty in feeding themself, gathered information on it, or actually changed something in the environment to try to solve this problem?
a. yes b. no

152. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

153. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

154. Is it working? a. yes b. no

101. How have you handled the problem of the person having difficulty in toileting? 1 2 3 4 5 6 7 8 9 10

155. Have you thought about physical environmental solutions to the problem of the person having difficulty in toileting, gathered information on it, or actually changed something in the environment to try to solve this problem?
a. yes b. no

156. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

157. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

158. Is it working? a. yes b. no

102. How have you handled the problem of the person having difficulty in bathing or showering by self? 1 2 3 4 5 6 7 8 9 10

159. Have you thought about physical environmental solutions to the problem of the person having difficulty in bathing or showering by themself, gathered information on it, or actually changed something in the environment to try to solve this problem? a. yes b. no

160. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

161. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

162. Is it working? a. yes b. no

103. How have you handled the problem of the person having difficulty in grooming self (neatness, hair, nails, face, clothing)? 1 2 3 4 5 6 7 8 9 10

163. Have you thought about physical environmental solutions to the problem of the person having difficulty grooming themself, gathered information on it,or actually changed something in the environment to try to solve this problem?
a. yes b. no

164. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

165. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

166. Is it working? a. yes b. no

104. How have you handled the problem of the person having difficulty in moving around within residence? 1 2 3 4 5 6 7 8 9 10

167. Have you thought about physical environmental solutions to the problem of the person having difficulty moving around within the residence, gathered information on it, or actually changed something in the environment to try to solve this problem? a. yes b. no

168. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

169. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

170. Is it working? a. yes b. no

105. Other (specify)_____? 1 2 3 4 5 6 7 8 9 10

171. Have you thought about physical environmental solutions to this problem, gathered information on it, or actually did something in the environment to try to solve this problem? a. yes b. no

172. If environmental intervention has been used to handle this problem describe the environmental solution tried? _____
_____

173. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

174. Is it working? a. yes b. no

106. Other (specify)_____? 1 2 3 4 5 6 7 8 9 10

175. Have you thought about physical environmental solutions to this problem, gathered information on it, or actually changed something in the environment to try to solve this problem?
a. yes b. no

176. If environmental intervention has been used to handle this problem describe the environmental solution tried?

177. What was your intention behind the intervention?
a. prevention
b. rehabilitation
c. maintenance
d. help caregiver
e. other _____
(specify) _____

178. Is it working? a. yes b. no

179. Are there other changes in the environment you would like to have changed but haven't? a. yes b. no
If yes, please specify.

_____

_____

Appendix F

Physical Self Maintenance Scale

Score			
	A.	**Toilet**	
1		1.	Cares for self at toilet completely, no incontinence.
0		2.	Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most accidents).
0		3.	Soiling or wetting while asleep more than once a week.
0		4.	Soiling or wetting while awake more than once a week.
0		5.	No control of bowels or bladder.
	B.	**Feeding**	
1		1.	Eats without assistance.
0		2.	Eats with minor assistance at meal times and or with special preparation of food, or help in cleaning up after meals.
0		3.	Feeds self with moderate assistance an is untidy.
0		4.	Requires extensive assistance for all meals.
0		5.	Does not feed self at all and resists efforts of others to feed him.
	C.	**Dressing**	
1		1.	Dresses, undresses and selects clothes from own wardrobe.
0		2.	Dresses and undresses self, with minor assistance.
0		3.	Needs moderate assistance in dressing or selection of clothes.
0		4.	Needs major assistance in dressing, but cooperates with efforts of others to help.
0		5.	Completely unable to dress self and resists efforts of others to help.
	D.	**Grooming** (neatness, hair, nails, hands, face, clothing)	
1		1.	Always neatly dressed, well-groomed, without assistance.
0		2.	Grooms self adequately with occasional minor assistance, e.g. shaving.
0		3.	Needs moderate and regular assistance or supervision in grooming.
0		4.	Needs total grooming care, but can remain well-groomed after help from others.
0		5.	Actively negates all efforts of others to maintain grooming.

E. **Physical Ambulation**

1 1. Goes about grounds or city.

0 2. Ambulates within residence or about one block distance.

0 3. Ambulates with assistance of (check one) a ( ) another person, b ( ) railing, c ( ) cane, d ( ) walker, e ( ) wheelchair.
   1. Gets in and out without help.
   2. Needs help in getting in and out.

0 4. Sits unsupported in chair or wheelchair, but cannot propel self without help.

0 5. Bedridden more than half the time.

F. **Bathing**

1 1. Bathes self (tub, shower, sponge bath) without help.

0 2. Bathes self with help in getting in and out of tub.

0 3. Washes face and hands only, but cannot bathe rest of body.

0 4. Does not try to wash self and resists efforts to keep him clean.

Appendix G

Memory and Behavior Problem Checklist

Instructions: Say to the caregiver "I am going to read you a list of common problems. Tell me if any of these problems have occurred during the past week. If so, how often have they occurred? If not, has this problem ever occurred?" (Probe for response that matches one of the frequency choices.)

Frequency Ratings

0=never occurred
1=had occurred, but not in past week
2=has occurred 1 or 2 times in past week
3=has occurred 3 to 6 times in past week
4=occurs daily or more often
7=would occur if not supervised by caregiver
(e.g. wandering except door is locked)
8=patient never performed this task

Behaviors

1. Wandering
2. Asking repetitive questions
3. Hiding Things (e.g. money, jewelry)
4. Being suspicious or accusative
5. Losing or misplacing things
6. Not recognizing familiar people
7. Forgetting what day it is
8. Not completing tasks
9. Destroying property
10. Doing things that embarrass you
11. Waking you up at night
12. Being constantly restless
13. Being constantly talkative
14. Engaging in behavior potentially dangerous to others (describe)
15. Engaging in behavior potentially dangerous to self (describe)
16. Reliving situations from the past
17. Seeing or hearing things that are not there (hallucinations or illusions)
18. Unable to dress self (either partially or totally)
19. Unable to feed self
20. Unable to bathe or shower by self
21. Unable to shave or put on make-up by self
22. Incontinent of bowel or bladder
23. Unable to prepare meals
24. Unable to clean the house

25. Unable to use the phone
26. Unable to handle money
27. Unable to shop
28. Unable to do other simple tasks (e.g. put groceries away, simple repairs)
29. Other:

* Rater judges whether behavior is dangerous or merely troublesome.

Appendix H

Daily Coping Categories

Category	Description of the Coping Category
Distraction	Diverted attention away from the problem by thinking about other things or engaging in some activity.
Situation Redefinition	Tried to see the problem in a different light that made it seem more bearable.
Direct Action	Thought about solutions to the problem, gathered information about it, or actually did something to try to solve it.
Catharsis	Expressed emotions in response to the problem to reduce tension, anxiety, or frustration.
Acceptance	Accepted that the problem had occurred, but that nothing could be done about it.
Seeking Social Support	Sought or found emotional support from loved ones, friends, or professionals.
Relaxation	Did something with the implicit intention of relaxing.
Religion	Sought or found spiritual comfort and support.

Appendix I

Other Problems Reported by Caregivers Divided by Stage

Stage 4

1. Patient verbally abusive (argumentive)

Stage 5

1. Patient verbally abusive
2. Patient depression
3. Patient has low self confidence
4. Patient has difficulty making decisions
5. Patient feeling that they are a burden
6. Patient resents/resists help from others
7. Patient having difficulty adjusting to move into relative's home
8. Patient constantly getting into things and making a mess (ex. patient takes food from freezer and hides it in bedroom drawers, rearranges drawers or empties closets, etc.)
9. Patient closing windows (during the summer)
10. Patient is overly friendly to strangers (ex. stopping cars and inviting strangers into their home or offering the strangers gum)
11. Patient jealous or suspicious (ex. thinks the caregiver is having an affair with young hired help)
12. Patient won't let caregiver out of their sight (no privacy)
13. Patient asks constant questions
14. Patient always entertaining guests (brings out pictures and treasures from patient's past to share)
15. Difficult to take patient out in public (patient gets lost, needs to stay beside caregiver at all times)
16. Caregiver has difficulty finding someone to stay with patient when they have to be away
16. Caregiver has difficulty juggling between family and patient responsibilities and demands

Stage 6

1. Patient combative
2. Patient has difficulty riding in car or may have difficulty getting in and out of car
3. Patient's failing memory is hard for caregiver to accept
4. Patient doesn't recognize spouse
5. Patient cannot express themself verbally (unable to talk)
6. Difficult to take patient out in public (patient too slow or too impatient)
7. Patient engaging in repetitive and/or annoying behaviors (ex. taking the trash out 3 times a day or clicking their teeth)

8. Patient overly affectionate
9. Caregiver guilt
10. Caregiver worries about patient safety (ex. falling)
11. Caregiver has difficulty dealing with the restriction of their life
12. Caregiver, caring for a spouse, has difficulty adjusting to the changes in their personal relationships with patient (ex. sex life)

Stage 7

1. Patient slowness
2. Patient cannot express themself verbally (unable to talk)
3. Bedridden patient need for repositioning every 2-3 hours
4. Caregiver experiencing physical stress from lifting and turning bedridden patient
5. Caregiver has difficulty dealing with constant disruption of daily living
6. Caregiver has difficulty finding help (24 hour job)

ENVIRONMENTAL COPING EMPLOYED IN THE HOME ENVIRONMENTS OF PERSONS WITH ALZHEIMER'S DISEASE

by

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B.S., Kansas State University, 1987

AN ABSTRACT OF A THESIS

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ABSTRACT

Research suggests that the design of a sensitive, therapeutically supportive environment can play an important role in the management and care of patients with Alzheimer's disease by reducing the burden of caregiving. This study examines changes in the residential environment which caregivers made in response to 16 memory and behavior problems patients experienced, and how these changes affected the perceptions of stress and control reported by caregivers. Thirty primary caregivers of patients at home participated in the study. First, the study describes the types of environmental interventions employed by caregivers, and those which they perceived as being effective. Second, it focuses on the role of managing the physical environment of the patient's home as a source of stress and control perceived by caregivers. Third, it examines the use of environmental interventions within the context of all coping strategies caregivers used to respond to memory and behavior problems. Finally, it offers suggestions for residential environmental interventions to be used by designers and caregivers, based on the information obtained.

Environmental intervention was the third most frequently used coping strategy, following direct action and acceptance. Environmental intervention was used 13% of the time and was employed for at least one problem by 83% of the caregivers. Of the environmental interventions tried, 87%

were successful. Environmental interventions varied by problem and stage of Alzheimer's disease, with caregivers caring for patients in the later stages reporting twice as much environmental intervention as caregivers caring for patients in earlier stages. Caregivers' efforts to manage problems through environmental interventions were not significant predictors of the stress or control perceived by caregivers. Furthermore, when caregivers were grouped on the basis of characteristics of the person or the home environment, no significant differences were identified. The only significant difference found was that caregivers of more impaired patients used more environmental management.

In general, coping strategies employed by caregivers in this study support previous design recommendations for therapeutic residential environments. Although the environment may play an important role in coping with the complex problems associated with Alzheimer's disease, the impacts of environmental management on caregivers' perceived stress and control remain unclear.